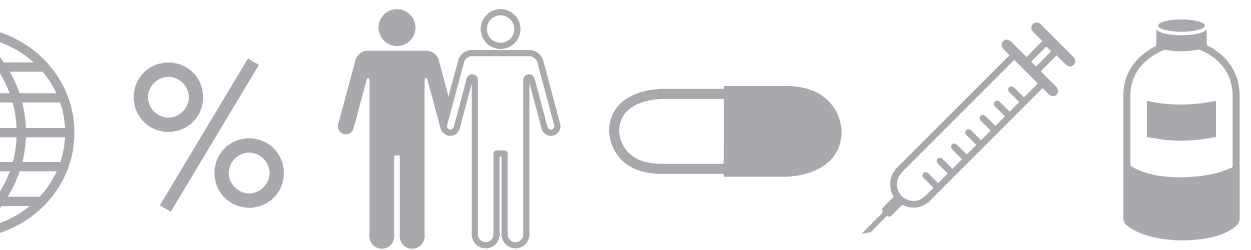
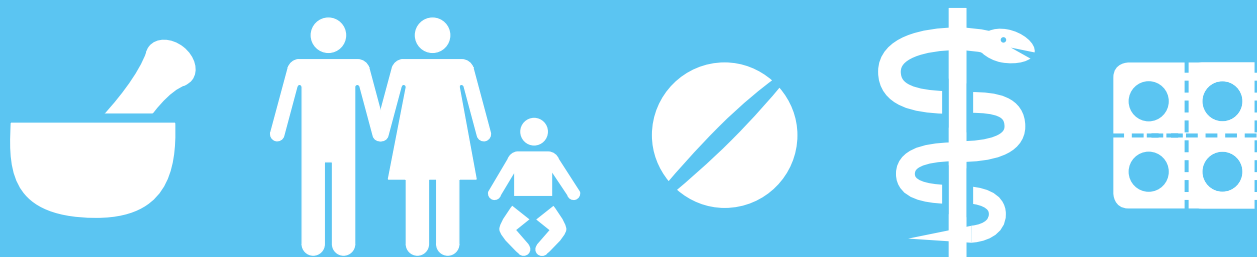


Pills, Politics and Practice



25 YEARS OF PROMOTING PEOPLE-CENTRED MEDICINES POLICY

1981 – 2006



Dear Friends,



It is hard to believe that Health Action International (HAI) has been a part of many of our lives for 25 years now. For many of us, the issues and people involved in HAI have become such an integral part of what we do that

it's hard to remember life before HAI. But thinking back on all that has happened during its existence and looking at HAI's impressive record of battles won and significant achievements reached, one thing is certain: the social and political environment surrounding pharmaceutical policy was a far poorer place before 1981! Who can forget that HAI was there at the beginning of the World Health Organization's (WHO) Essential Drugs Concept? That it strongly supported the WHO's launch of the Revised Drug Strategy? That it had a hand in helping to shape the way that national drug policies were formulated? That it was (and remains) a leader in the promotion of rational drug use and ethical drug promotion? That HAI was an early partner in the global coalition of groups working to increase access to essential medicines?

Trying to write down the history of HAI in a booklet like this seems odd and incomplete. While you'll see there are pages and pages of examples illustrating successful campaigns, crucial events, milestones along the way, and landmark publications, the end results seem like only half of the story. How can one describe in a few words the hours of discussion held to develop a strategy to put an interna-

tional campaign into motion? How do you express the frustration and strong determination felt after a particular battle was only half won – or sometimes, completely lost? The entries in this booklet can't show the expertise, inspiration and mentoring given by HAI members or contacts who were there when crucial things happened. It can't do justice to the frequent late nights needed at crucial meetings, the often heated debates, the corridor conversations occurring outside meeting rooms and the sheer hard work carried out before any success was achieved.

I hope as you read through this booklet, good memories will come back to you about campaigns and activities in which you've taken part. No doubt you'll also remember reading or hearing about other issues tackled by members of the network that might have been outside your own work but on which HAI took a stand. Newer members will also have a chance to read about some of the events and work carried out before they became active in the network. In addition, I hope you will feel pride about HAI and all that it has achieved in the past quarter of a century. The network is only as strong as its members and if this booklet is any indicator, our network is very strong!

On the following pages you'll see a summary of the things HAI has achieved over the years and hear from many of those involved in making these things happen. The quotes given by various HAI Europe members and other contacts reveal how HAI has influenced many of us and helped us in our own work. Their stories show how the network attracts very different kinds of people looking for different things from HAI. They also show how the network has grown and changed over the

years to respond to its members' priorities and changes in the world around it. Yet while HAI has matured over the years, its basic goals remain unchanged. The reason for this is clear:

The concepts of rational use, essential drugs and access which have framed so much of our working lives, which have even dominated some of our entire careers, refuse to go away! The political climate has changed dramatically during HAI's existence. When HAI started in 1981, I'm not even sure we really understood where the globalisation of the medicine market was going to take us. Many issues have been difficult and at times allies have been few and the forces against HAI strong and well funded. But HAI, gaining strength from the expertise in its network and its confidence that these issues are important for people around the world, has always been able to respond to shifts in the medicines paradigm with a vigour and enthusiasm that amaze me.

Today, almost every time I pick up a medical or health journal, I know that someone in the HAI network will have an opinion on just about every issue the journal contains. The wealth of knowledge and combined experience found within HAI is astonishing. And long may it continue – thankfully many of our founding members remain actively engaged in HAI's work. Moreover, they continue to share their expertise and experience with a new generation of HAI activists, well versed in the international political economy, the sociology of health and medical anthropology, alongside those involved in the more traditional medical and pharmacy fields. Whatever their backgrounds, all of them share the same determination, tenacity and scepticism that started HAI all those years ago.

HAI now enters its next 25 years with renewed enthusiasm to put people-centred medicines policy at the centre of the global debate on medicines. It also goes forward with the confidence that the strength of the network will remain the driving force behind HAI's astonishing success.

Let me extend a very big thank you to all of you who have helped HAI during its first 25 years. This booklet is your history too.

With very best wishes,

Anita Hardon
Chair, HAI Foundation Board

September 2006

In 1981, HAI began working for more rational drug use in countries around the world. Although priorities have changed over the years and working methods with them, the underlying objectives of the network continue to guide its work: improve access to essential medicines and promote their rational use. Below is a collection of some of the activities taken up by HAI Europe groups, groups in other parts of the network and HAI's coordinating offices during the past 25 years, as well as some significant events and actions carried out by others. This list is far from exhaustive, and we hope that many more will be added in the coming years. Accompanying the timeline are interviews and quotes from many HAI Europe members, staff and friends from other regions of HAI. Their words help put HAI's 25 years into perspective and reveal the challenges that still exist.

Interview with Virginia Beardshaw

“Starting from scratch”

VIRGINIA BEARDSHAW WAS HAI EUROPE’S FIRST COORDINATOR, WORKING FROM 1982 TO 1986. STARTING IN AN UPSTAIRS ROOM AT THE INTERNATIONAL ORGANIZATION OF CONSUMERS UNIONS (IOCU) IN THE HAGUE, SHE WORKED TO BUILD THE NETWORK WITH THE HELP OF KEY HAI MEMBERS. SHE ALSO REPRESENTED HAI AT SOME CRUCIAL MEETINGS ON PHARMACEUTICAL POLICY IN THE EARLY 1980’S. BELOW, SHE LOOKS BACK AT WHAT IT WAS LIKE TO START A NETWORK WITH NEXT TO NOTHING. VIRGINIA IS NOW CHIEF EXECUTIVE OF I CAN, THE UK CHILDREN’S CHARITY.

WHY WAS HAI STARTED IN 1981?

There was a sense in many quarters that pharmaceutical marketing was out of control in developing countries. People were interested in essential drugs and the problem of there being too many “me too” products in the developed world. One big attraction was that these were not just developing country issues. They were relevant for all of us: issues like rational prescribing, limited lists, rational pharmaceutical use and ethical marketing had resonance in Europe as well as developing countries.

It was clear that in a number of places, people were asking the same kind of questions. There were multiple centres of concern across Europe reaching into southern countries. There were a number of people in Europe researching pharmaceutical use, including Charles [Medawar], BUKO, Wemos, Andy Chetley at War on Want, who was probably the most gifted campaigner we had.

Dianna Melrose’s book *Bitter Pills*, which was published by

Oxfam in 1983 was a landmark publication, bringing together important evidence on pharmaceuticals and throwing Oxfam’s credibility behind the issue. WHO’s Essential Drugs Programme gave us the policy backdrop we needed. It was a very radical, far-sighted programme and gave us an international standard.

So people began making connections. You have to remember how different the world was then. We did our first networking in HAI by telex! International phone calls were expensive. We had no Internet and no email. Even faxes had yet to be invented. No office computers either – I thought myself very privileged to have an electric typewriter, which was a huge improvement on the 1950s manual I had been using at Social Audit. And there was no mass air travel to the same extent as there is today.

HOW WERE CONTACTS MADE IN THE EARLY DAYS?

A series of contacts were made haphazardly through research visits, and books like Dianna’s had a very long reach

because of Oxfam’s links into the poorest countries and communities. That was also true of Andy Chetley’s work. BUKO and others had ways of reaching out. They were like tentacles reaching out. When we could, I set up a desk at the IOCU office in the Emmastraat [in The Hague, the Netherlands] and I commuted from Brussels to The Hague. IOCU was important in the early days, it had an international organisational base and we could involve its members.

HOW DID YOU GET INVOLVED IN HAI?

I was working for Social Audit in the late ’70s and early ’80s. In 1982 I had just published what became Social Audit’s bestseller, a book about whistleblowers. Then, for family reasons, I moved to Brussels. But Charles [Medawar] and Andrew [Herxheimer] decided I was the ideal person to start the network.

I had no idea how to set up an NGO campaigning network, no one did. Now the word seems a total cliché, but back then we had to invent what it was. I take great pride in the

fact that HAI is still going. We started with nothing but IOCU’s international connections and loads of good people who gave us the contacts and connections. Plus, WHO was taking interest in rational drug use. Those were the ingredients.

I started in July 1982. I was alone at 9 Emmastraat. I used to spend the night there. Thinking about it now, it was quite crazy. It was not in any way a conventional job. Now when I look back at how we made something from nothing, it seems quite amazing.

I feel lucky to have been a pioneer, and to mould and shape things from scratch. Now everything is so formal, everyone has job descriptions, but then we were making it up as we went along. There was absolutely no governance structure. Accountability such as it was, was through IOCU, but that was pretty vague.

WHO WERE THE CORE PEOPLE INVOLVED?

There was Andrew Herxheimer. I remember he used to ring me at home. I had a little baby and I’d have her in my arms and he’d talk to me for hours on the phone. They all did. I didn’t think anything of it, but now if any of my staff did the same I would be obliged to have discussions with them about work/life balance and

setting boundaries between work and private life.

Anwar Fazal was working for IOCU in Penang. Lars Brock came in to run IOCU in The Hague. Charles [Medawar] was involved too. Dianna Melrose was vital, and became a great personal friend, as did Janita Janssen, with whom I have sadly lost touch. Ruth Vermeer at IOCU was my main contact in The Hague.

People at IOCU were nervous about HAI in the beginning. Here was this body without any clear governance. No one in the consumer movement knew if someone would go ahead and sue us. It was not as big a concern to them as it should have been! There were no clear ideas on what we should be doing or how we should operate.

HOW DID YOU KNOW WHAT TO DO FIRST?

I am good at starting from the cold. I decided to make an application to a Scandinavian funder. So I put together an application to an august body for US\$200,000 – and 25 years ago that was a lot of money. And to my complete surprise they just sent us a check! That was one thing we did right. That early support followed a visit I made to Geneva, where I met people from the WHO Drug Action Programme including Pascale Brudon. She



really helped smooth the way at WHO and I always stayed with her when I came to Geneva. I met a lot of people including those key Scandinavian contacts on that first trip.

TELL US ABOUT THE EARLY DAYS...

We went to the Assemblies, and one year we even put out a daily newspaper. In ’83 we went for the first time, I think. It was Dianna and me and a contingent from Penang. What was the reaction to our presence? WHO officials were really taken aback and the pharmaceutical industry was not happy. Talk about a guerilla attack! We were very audacious. If we had known the extent of the forces marshalled against us, I wonder if we would have done it. But it was fun and we also knew we were right. We were also pretty careful. You don’t campaign against what is now called Big Pharma without taking care, which we did. We also had good expertise

“What impresses me now is how far-sighted we were”

behind us with people like Graham Dukes, Andrew Herxheimer and others.

But the really big thing was the Nairobi conference on essential drugs in December 1985. What is amazing is that it happened at all. It happened because of us. We pressurized WHO to get the essential drugs programme on the agenda and to dedicate an international meeting to it. WHO's Director General Mahler – a very impressive and ethical man, a true leader – I know he thought we were a damn nuisance. He had a fierce word with me from the chair in Nairobi at one point, and I remember feeling very mortified and put down. Thinking about it 20 years on, I realize that dealing with us must have been very tricky for him politically. I can understand now why we were treated as a wild card.

HAI was formally represented in Nairobi. We had a place at the table with a name plate and everything. We had geared up from an empty desk and chair in Emmastraat in '82 to this major international meeting in '85. We were instrumental in getting this international seminar on this important subject. I think we did amazingly well.

We were an official NGO at the meeting. I was the first

person from HAI to speak as the meeting opened. I remember that, perhaps pretentiously, I quoted some famous philosopher in my speech. I could feel the whole room relax. I added in the quote because I wanted to demonstrate that we weren't a bunch of wild extremists, and that we knew how to behave at an international meeting. It worked! All the other delegates began referring to the quotation, or quoting other wise words in their speeches, so it broke the ice. However, none of the officials or the pharmaceutical industry really knew how to take us. The industry was furious!

That Nairobi meeting was also the first time I really focused on AIDS. People were talking about the level of HIV/AIDS in the Kenyan population, particularly among Nairobi's prostitutes. It was quite early in terms of the pandemic.

What impresses me now is how far-sighted we were. The issues we picked were of global significance, with far-reaching, long-term consequences for world health. The truth of this came home to me when I joined the UK National Health Service in the '90s and found that issues of rational prescribing and limited lists were only just being tackled. Looking back now, I only wish we could have done more and

had more of an impact then on subjects like antibiotic resistance.

HOW DID YOU DO SO MUCH BEING ON YOUR OWN?

At times I was very lonely, but I also liked the independence I had. And I really did feel that I was useful as a central point, pulling everything together. That's why the HAI meetings were important. They weren't annual at that point; we just met whenever we decided to have one. The first two were held in my house in Brussels. That's typical of how things were organised at the time and typical of me. I never ever want to spend money on expensive venues!

DID YOU NOTICE THAT THINGS CHANGED IN THE FOUR YEARS YOU WERE THERE?

Yes, the fourth or fifth HAI meeting took place in Bielefeld, Germany and was organised by BUKO. It was interesting. There must have been 40 people in the room and it was absolutely clear we were going to have to move to a different style of working with proper representation. The days of informality had finished. We needed to be more organised, with proper systems of governance and accountability.

There was quite a bit of, not exactly conflict at the meeting,

but it wasn't smooth. You could no longer rely on informal relations between people who knew each other very well. HAI had gotten too big. For me it was crystal clear that a new phase was starting. The need to develop more formal structures was inevitable. I was lucky to be there in the pioneering days.

WERE YOU INVOLVED IN BRINGING CATHERINE TO HAI AS THE NEXT COORDINATOR?

I went to school with Catherine and I coaxed her into taking the job. She was quite reluctant initially. Things were not formalised; there was certainly no job description, so I just said to everyone, "Look, I

know someone who can take over". I was backing out and going back to the UK and I knew we had started something important and I didn't want it to fizzle out. I wanted someone good. I don't remember what the governance structure was then, but I basically convinced them.

WHAT CAN YOU SAY ABOUT HAI IN THOSE DAYS?

What's important is how bold we were and how committed. It really was a crazy life – juggling tiny children and international issues. And doing it without the close communications which we entirely take for granted nowadays. It was hard to get in touch with Penang and Montevideo

[where the other HAI coordinators were working]. The lobby teams in Geneva had no mobile phones or text messaging, we just pounded the corridors. But we had a tremendous amount of fun and had excellent people.

HAI was very fleet of foot. And we were soundly evidence based. That, I think, was my strongest contribution as founding European Coordinator – I was very strong on accuracy, and basing everything we did on proper evidence. The proof of it is that we succeeded in influencing big international issues and we created something that is still going, still lively and still agile. And we didn't get sued!

Reflections on HAI by Charles Medawar

Bitter-sweet HAI

CHARLES MEDAWAR WAS ONE OF HAI'S FOUNDERS. HE TOOK AN ACTIVE ROLE IN HELPING THE NETWORK SURVIVE AND FLOURISH WHEN THE DECISION WAS MADE TO SEPARATE HAI EUROPE FROM IOCU. THROUGHOUT HAI'S HISTORY, CHARLES HAS BEEN AN ACTIVE SUPPORTER OF THE NETWORK'S CAMPAIGNS AND GOALS AND HAS FOUGHT FOR MANY RELATED CONSUMER HEALTH ISSUES THROUGH HIS OWN ORGANISATION, SOCIAL AUDIT, BASED IN LONDON.

HAI was conceived, by acclamation, at the close of a three-day, North-South conference that brought together health and

consumer non-governmental organisations (NGOs) and activists, I think, for the very first time. The conference was

in Geneva and discreetly supported by WHO – then, I'm afraid, a very much healthier organisation than it is today.

“Our independence is, and always has been, central to our vitality”



I still have a copy of the (wax stencilled) inaugural press release that launched what we became, and I clearly remember helping to draft it. It was on 29 May 1981: HAI was a commitment to develop as “an international antibody (to) resist the ill-treatment of consumers by multinational drug companies”.

Re-reading that press release for the first time in many years (yes, my filing system is that good) I have these main thoughts: a) our diagnosis was very sharp, far ahead of its time, but b) that is also to admit that the problems we anticipated got worse; and c) that HAI and what it stands for must be an essential part of any good health solution.

We have demonstrated that in addressing many different issues, notably drug innovation

and promotion and problems of access. We express what HAI stands for in our own ways: they include serious academic research, imaginative and well-focused campaigns, potent representation, catalytic and direct organisation and, so often, such fruitful collaborations.

HAI has mellowed over the years, but it has never softened on points of principle and, unlike so many organisations in this field, it has remained independent, never tainted by prospects, promises and dollars. Antidotes and antibodies seem needed more than ever, if only to resist such pervasive denial of the impact of malign and unhealthy corporate behaviour. Corporate behaviour? Pharmaceutical companies are still the drivers of the problem, but it seems natural that our focus should have shifted somewhat, to focus more on the steering and brakes. Our governments, ever ready to trumpet their commitment to the values of the people and to pose as the ‘competent authorities’, have much to answer for as well. So, in my view, does the leadership of the medical profession – by design and default (and also far beyond my terms).

Why is HAI vital to me and you? It is because we are a unique collective of minds; we have the

qualitative, if not quantitative, capacity to identify solutions well geared to the spirit of ‘health for all’. Our independence is, and always has been, central to our vitality. It has been key to our understanding – that the quality of human existence overwhelmingly depends on proper and decent corporate/institutional/leadership behaviour.

Happy Birthday, dear HAI: yet there is still almost everything to do. Fortunately, we have retained and augmented the strength of spirit to refuse policies that crush healthy endeavour. We know that countless lives are blighted and lost, not for lack of technology, but mainly for the failure to understand, apply and control it. HAI’s future, alas, is almost guaranteed by the extent and impact of behaviour that is unscientific, unreasonable, unfair, unwise, self-interested or otherwise poor.

Happy Anniversary Indeed (HAI) – and don’t we all wish that these were not still the main issues we need to address, to secure the health we all deserve.

1981

- The World Health Organization’s (WHO) Action Programme on Essential Drugs is launched.
- HAI is created in May after a three-day seminar on pharmaceuticals attended by representatives from 50 organisations in 26 countries
- An international campaign on the risks of Lomotil (diphenoxylate) and clioquinol begins.
- The International Federation of Pharmaceutical Manufacturers Associations (IFPMA) launches a voluntary international code of marketing.
- HAI publishes a discussion document on the IFPMA code which includes a proposed draft international code covering research, production and marketing.
- In September 1981, GD Searle revises its labelling of Lomotil to recommend against its use by children under two years of age, as a result of an international campaign spearheaded by the UK-based group, Social Audit.
- In October 1981, the first issue of *HAI News* is published.
- The International Research Group for Drug Legislation and Programmes publishes *Pharmaceuticals and health policy: International perspectives on provision and control of medicines*. It is later reprinted by HAI as a paperback and widely distributed as an advocacy document.

1982

- Bangladesh introduces a progressive national drug policy.
- BUKO Pharma-Kampagne holds its first action week in Germany to draw attention to the conduct of German pharmaceutical companies in the Third World.
- HAI's presents its draft code on pharmaceuticals at an United Nations Conference on Trade and Development (UNCTAD) meeting in the hopes that UNCTAD will collaborate with WHO and other concerned agencies to develop a UN international code on the marketing of and rational use of pharmaceuticals.
- The UN General Assembly calls for an international list of banned, not approved, withdrawn or severely restricted products.
- Oxfam publishes *Bitter Pills* by Dianna Melrose; Mike Muller's book, *The Health of Nations* also appears – both are highly critical of the activities of the pharmaceutical industry and stress the need for more rational approaches to the use of medicines.
- Opren/Oraflex (benoxaprofen), an anti-arthritic drug, is withdrawn worldwide.
- High-dose oestrogen/progesterone products (often misused to induce abortion) are banned in India.
- Phenacetin, an analgesic, is banned in Brazil, India and Japan.
- Ciba-Geigy announces it will gradually phase out products containing clioquinol over a five-year period, as a result of the international campaign led by Swedish doctor, Olle Hansson and the International Organization of Consumer Unions (IOCU).
- HAI produces its first briefing paper on drug policy for the delegates of the 35th World Health Assembly entitled *WHO and the pharmaceutical industry*.

Memories on HAI's early days by Wilbert Bannenberg

“Part of a new movement”

WILBERT BANNENBERG IS A PUBLIC HEALTH PHYSICIAN BASED IN THE NETHERLANDS. HE IS WORKING AS A CONSULTANT IN DEVELOPING COUNTRIES, MOSTLY AFRICA. BESIDES ADVISING MINISTRIES OF HEALTH, HE ALSO ADVISES NGOS (MSF, WEMOS), AND IS A MODERATOR OF THE E-DRUG DISCUSSION ON THE INTERNET. HE SERVED FOR EIGHT YEARS ON HAI'S FOUNDATION BOARD AND REMAINS A MEMBER OF HAI.

Unfortunately I was not present when HAI was founded at a meeting in Geneva, in May 1981, after the baby food activists had successfully lobbied for a code of conduct in the WHO Assembly. That year (1981) I was working as a volunteer for the Dutch NGO Wemos. Four of us were preparing a conference on “Health and Politics”. As young doctors, we realized that poverty, unfair trade, exploitation of developing countries and politics contributed more to poor health than viruses, bacteria or tropical diseases. What could we do?

The double standards used by the pharmaceutical industry were an important topic at the conference. During visits to Africa I had discovered that the Dutch drug company Organon was marketing anabolic steroids for the treatment of malnutrition in children, something that was unthinkable in the Netherlands. Our conference in Amsterdam (November 1981) attracted some early HAI members: I remember interesting discussions with Marcel Bühler, Leo Locher and Jörg Schaaber. Being Swiss and

German activists, they had many more drug companies exporting bad products to developing countries. We agreed to collaborate.

It was Jörg Schaaber of BUKO Pharma-Kampagne who invited me to the newly formed HAI. On a cold February day we travelled by train and boat to the UK, to join our first HAI meeting. In London we found a group of hard-working individuals: Dianna Melrose was researching her *Bitter Pills* book for Oxfam. Andrew Herxheimer was a critical pharmacologist, and identified campaign target drugs. Charles Medawar of Social Audit had already published several critical reviews of drug companies' marketing. His assistant was Virginia Beardshaw, who would soon become the first HAI coordinator.

The International Organization of Consumer Unions (IOCU) adopted HAI as one of its projects. Its Asian coordinator, Anwar Fazal, liked networks: besides baby food (IBFAN) and pharmaceuticals (HAI), he also helped to develop networks on pesticides (PAN)

and seeds (SAN). HAI got office space in IOCU's international office in the Netherlands. I remember many trips to Emmastraat 9 in The Hague to assist Virginia Beardshaw in setting up the HAI network.

Our first need was to raise awareness: the blatant double standards in drug marketing during the early 1980s were an easy campaign target. So in May 1982, some 25 HAI activists joined powers in Geneva to lobby for a WHO Code of Marketing Practices at the World Health Assembly. Lobbying a WHO Assembly was new to all of us: some of us wore jackets for the first time! I remember helping colleague activists with the knot in their ties! It was very encouraging to be part of a new movement, and work with colleagues from other countries and continents.

‘Fort Knox’ was our bunker, where we slept in bunk beds, ate muesli, and had endless plenary meetings to discuss our strategies. We could not (yet) afford wine or expensive Geneva restaurants, so we were quite happy to lobby delegates at the daily cocktail



parties at the WHO. Dr. Mahler was the visionary Director General at that time in WHO, who had developed the concepts of Primary Health Care and Essential Drugs. Drug companies were heavily opposed to these revolutionary concepts, and attacked the newly formed Drug Action Programme, headed by another visionary Dane: Dr. Ernst Lauridsen.

But the drug companies had learned some lessons from the baby-food industry debacle one year earlier, and weren't going to make the same mistakes. To forestall a compulsory code, they had developed a self-regulating 'voluntary' code of conduct under their lobby arm, the International Federation of Pharmaceutical Manufacturing Associations (IFPMA).

Drug companies had also lobbied several Western

governments to block our demand for a WHO Marketing Code for the drug industry. The IFPMA probably had an even bigger team than HAI at the WHO Assembly. The US, which was paying 25% of WHO's contribution, warned Dr. Mahler that they would leave the organisation if WHO went for a marketing code. Obviously, HAI didn't get its code....

HAI launched two books in Geneva: Dianna Melrose's *Bitter Pills*, and Mike Muller's *The Health of Nations*, both heavily criticizing the drug companies' behaviour in developing countries. Two years later, in 1984, we even had a complete journalists' team at the WHA producing a daily newspaper, exposing bad practices, and creating awareness among the delegates.

In the early 1980s, HAI also tried to stop the exports of ineffective or unsafe products from Europe. We tried hard lobbying the European Commission in Brussels. I remember long meetings in Virginia's house in Brussels, often ending with joint songs around Lars Broch or Ross Mountain on the piano. However, the EU, being a trade organisation, refused to stop or even control exports of unregistered products from Europe to developing countries.

The message was clear: HAI had to move action to developing countries, to help them stop the import of inappropriate products from their side. HAI sent me on a seven-month data collection and local awareness-raising safari through eastern and southern Africa in 1983.

Setting up drug-related networks in Africa was not easy; as most NGOs were busy trying to help poor communities and provide emergency assistance. Rather technical issues such as drug promotion or double standards weren't their first priorities. Drug companies also had substantial influence in African governments.

Communication was problematic in the early HAI days: air tickets were expensive, telephone lines were poor quality, and fax, email and mobile phones didn't yet exist. We worked with airmail letters, and then waited one month for an answer. If it was urgent, we could send telegraphic style one-minute telex messages. Computers did exist, but had a maximum of 32 or 64 Kbytes of memory and no hard disks. Writing a long article meant saving it in five different files!

My HAI Africa safari had shown me many problems with the use of medicines in Africa.

“Our first need was to raise awareness”

We decided to make campaign material to raise the awareness in both North and South. I still remember the London pub where we made a list of target drugs with Andy Chetley for the very successful *Problem Drugs* publication. Having failed to get an effective WHO Code of Marketing Practices, rational use of drugs became our new target. Drug companies tried hard, but failed to stop WHO from organising the landmark Nairobi Rational Use of Drugs meeting. I still remember the US being the only vote against the 'Nordic' resolution requesting WHO to organise the meeting.

By then, IOCU had set up other HAI networks in Asia and Latin America. The WHO Assemblies in Geneva became the meeting place of global HAI activists. Collaboration was not always easy, as we had such different backgrounds and priorities. HAI nearly collapsed at the 1986 Bogève meeting, but a new regional structure gave the needed autonomy to the regional organisations, while maintaining global collaboration through the meeting of HAI coordinators.

HAI Europe became a bit too big for IOCU, and, after a difficult process, we made ourselves autonomous.

Without funding or an office, but with sufficient ideas, action and volunteers, HAI invaded my attic in Amsterdam as an emergency office. The HAI Europe Foundation was set up for guarding the subsidies, and the HAI Europe Association was set up to ensure democracy.

After some fierce fundraising in Scandinavia, HAI Europe was able to employ its own staff and rent an office in a renovated warehouse in Amsterdam-West. Catherine Hodgkin succeeded Virginia Beardshaw, and Rose de Groot was hired as a 'temporary' secretary. HAI never moved, although the staff probably still dislikes the office when it becomes too hot to work in summer.

Global communication became essential for activists. The fax was really a brilliant invention! We got computers, a compuserve address, and we always travelled with a screwdriver and toolbox to fix telephone sockets in hotel rooms to connect our modems.

Annual HAI meetings were organised by members in several European countries. There was always a public seminar, to create some local awareness, or to launch a new publication. The next day, HAI staff and members would exchange reports and ideas

on what action to take. In the evenings, many new campaigns were planned over a glass of beer or red wine.

HAI was growing and getting older: time to train the next generation! From all over Europe they came in 1986 to Sweden for the famous, one and only 'HAI Summer School'. Surrounded by fresh air and forests, aspirant HAI activists learned about the four phases of drug research, and about industry's tricks, acquired skills in lobbying and computing, told each other about successes and failures, and planned campaigns. In the evenings, we socialized, and made bonds for life.

Twenty years later, we have grown up, gotten married, started jobs, had children, become experts and travelled the world. New issues have come: TRIPS, access, and pharmaco-economics. New organisations joined the debate, such as MSF and CP TECH. HAI regions are alive and kicking. However, in my work as a public health consultant in Africa, I encounter medicine problems daily. There is enough work for HAI to keep going for another 25 years!

1983

- Surendra J. Patel and other HAI contacts collaborate with Dr. Bala to produce *Pharmaceuticals and health in the Third World*, a collection of articles appearing in a special issue of the journal *World Development* and later published separately.
- The IOCU Regional Office for Asia and the Pacific conducts an international survey on the availability of anabolic steroids in 12 countries in both the industrialised and developing world. Findings show that while their use is tightly controlled in Northern countries, they are promoted widely in developing countries as tonics for children suffering from malnutrition and poor appetite. The Dutch group Wemos launches a campaign on the misuse of anabolic steroids, with a particular emphasis on those produced by the Dutch company Organon.
- The HAI Asia-Pacific network is officially launched with the publication of *The Penang Declaration on Rational Health Policies*.
- Olle Hansson reveals information about deaths due to two of Ciba-Geigy's anti-arthritis drugs: phenylbutazone and oxyphenbutazone. An international campaign pushing for their withdrawal is started.
- The journal *World Development* publishes a special issue on pharmaceuticals.
- The Medical Lobby for Appropriate Marketing (MaLAM) is launched with 53 subscribers.
- IOCU publishes *Prescription for Change* by Virginia Beardshaw.
- Spain bans 111 inessential or dangerous drugs; India bans 22 combination products; Pakistan bans clioquinol thanks to the efforts of HAI groups in Pakistan.
- Zomax (zomepirac) is withdrawn worldwide.
- Ciba-Geigy announces it will complete its withdrawal of products containing clioquinol by the end of 1983.
- Organon is found guilty of being careless in its marketing of anabolic steroids in the Third World by the Dutch pharmaceutical manufacturers association (NEFARMA). The decision comes as a result of the campaign conducted by Wemos.

Peter R. Mansfield,

General Practitioner and Director, Healthy Skepticism Inc.

“A forum for communication”

“Healthy Skepticism (formerly MaLAM (Medical Lobby for Appropriate Marketing)) has participated in the HAI network since we began in 1983 because HAI helped us find good contacts to work with around the world.

HAI's most significant achievement overall is providing a forum for communication and cooperation between network participants. This has been the foundation for many projects. Perhaps the project

that will have the biggest impact is the WHO/HAI guide to understanding and responding to drug promotion. It is still being written, so it is too early to judge, but it may make a major contribution to changing medical and pharmacy culture, with benefits for consumers.

From our perspective, HAI's main role remains the same and will remain crucial: to provide opportunities for network participants to work

together so as to achieve more than would be possible separately”.



Photo Staffan Svensson

An interview with Andrew Herxheimer

“HAI is a catalyst”

DR. ANDREW HERXHEIMER WAS ONE OF HAI'S FOUNDERS AND REMAINS AN ACTIVE MEMBER TODAY. HIS WORK IN THE UK FOR CONSUMERS ASSOCIATION AND THE INDEPENDENT DRUG BULLETIN THAT HE STARTED HAVE CONTRIBUTED TO MANY HAI CAMPAIGNS DURING THE PAST 25 YEARS. HERE, ANDREW TALKS ABOUT HOW HE BECAME INVOLVED IN HAI, WHY HE THOUGHT CONSUMERS AND DOCTORS NEEDED MORE INFORMATION ABOUT MEDICINES AND HOW HE BROUGHT THAT IDEA TO LIFE IN HIS OWN COUNTRY. AFTER SO MANY YEARS IN THE NETWORK, ANDREW STRESSES HIS BELIEF IN THE POWER OF A NETWORK LIKE HAI IN BRINGING DIVERSE PEOPLE TOGETHER FOR A COMMON GOAL.

HOW DID YOU FIRST GET INVOLVED IN HAI?

I went to the first meeting in Geneva when we decided to create it. I was working with Consumers Association (CA) and so was in touch with IOCU [International Organization of

Consumer Unions] then. And IOCU harboured HAI from the beginning in The Hague. We had no idea of course that it would all go this way. There was a feeling that it was necessary. It was a kind of alliance of people who wanted

the same things and decided to work together because it made it much easier and more likely to work than if you tried to do it yourself. When we met in Geneva, the director of UNCTAD [Surendra Patel] remarked that HAI was

“You see the agenda becoming broader, not more specialised”

German for shark, and said it was time for the fishes to join together.

The point is that the drug industry had become internationalised. Then government drug regulatory agencies had become more international after an interval. They were having meetings together and discussing things. But consumers were not internationalised, doctors and pharmacists were not internationalised, and that made them vulnerable, and they were very much exploited.

They were the target of dirty work. This was the central idea behind HAI: to build a counterweight to this great power of the multinationals. In a way, governments were always looked at as referees in society and that's where laws and regulations come from. But business was being done between the industry and governments. Regulatory agencies began to get together with the help of WHO-organised meetings.

Over the years HAI changed by becoming much more professional. I think we were beginners and amateurs early on. An organisation like HAI was new. There was great mystification, everyone wanted to know “Who are these people?” People wanted to find out and were writing about it in

industry newsletters. It was evident that they were worried and didn't understand it. I think they still don't. Though more people are starting to understand it now.

ISN'T IT UNUSUAL TO BE SOMEONE INTERESTED IN BOTH THE MEDICAL AND THE CONSUMER ASPECTS OF HEALTH POLICY?

When I was in my twenties and thirties, I was rather consumer aware. I was wanting to have value for money and wanted honest dealings. I was noticing prices and quality. I had consumer interest just as an ordinary person.

In 1957, CA was started in the UK by Michael Young, a famous, brilliant sociologist. The first consumer organisation with any clout was Consumers Union (CU) in America. It was the stimulus for him to start the organisation in the UK. People were gloomy about its chances, said it wouldn't last long, that it would be sued. But it grew and grew and grew. It was very successful.

I decided that doing research on drugs to investigate what one drug does to one function or problem and publishing it was a waste of time. People were not using the knowledge that already existed. It was a much greater priority to get

people to use what's already known. But how? You can't trust industry. They just want to sell products. You can't use medical journals; they're full of industry ads. You need something independent. In New York, two people who had long worked for CU had started *The Medical Letter on Drugs and Therapeutics* in 1959. I saw it and thought we needed something like it in the UK. Here, the *Medical Letter* was distributed only in Northern Ireland, but I thought we needed something for the whole UK, something professional, not done on a shoestring.

But how could this be published? Who could do it? Well CA would be the right sort of thing. I proposed it to them. They hadn't published anything that wasn't directly for consumers, but I said that consumers were treated by doctors and so they would benefit from it. And so it started in 1962. First we called it the *British edition of the Medical Letter*. The *Medical Letter* editors in the US worried a lot even about little changes we made, and we also needed different articles that weren't relevant for them, so we decided to separate and we changed the name to *Drug & Therapeutics Bulletin*. And I edited that part-time for 30 years.

During that time, I was the only doctor working regularly with CA. I became aware of IOCU which had been founded in 1960, and went to some of its congresses. Health issues began to be raised and in 1980, the IOCU Health Working Group was formed. Later CA and other consumer organisations started to publish health magazines.

The whole business of clioquinol (Enterovioform) had preceded HAI. It was just one of the scandals that led up to that first meeting. There was also the antibiotic chloramphenicol (Chloromycetin) which causes agranulocytosis. We had done a project on its package inserts to review the information given on usage and warnings. There were big differences internationally, a real scandal. We published an article about that in *The Lancet*. Then we did the same with clioquinol, an over-the-counter drug, to see what the labeling said. It was an absolute mess.

WAS THERE EVER A MOMENT WHEN YOU KNEW HAI WOULD BE A SUCCESS?

When you are in the thick of things you only think about the situation, you can't generalise, but later you can see the generalisations. Things we did were getting published in medical journals, then getting

into consumer journals. Then you saw things were also of interest to the media: radio, newspapers, magazines, TV. You start to think about general messages, systemic problems, government regulation, legislation, and see that things are moving from national to international, you see the role of WHO and UNCTAD. You see the agenda becoming broader, not more specialised. And that becomes the turning point.

Andy Chetley's *Problem Drugs* was another turning point. It showed it was obviously pointless to go campaign on drugs one by one. It wouldn't get us anywhere. It has to be done in a more systematic way, and higher upstream. It was clear that we had to do more on the organisational and legal side. We had to look at ideological and educational aspects as well.

DID THE NETWORK MISS IMPORTANT THINGS?

It's a self-regulating thing. If you don't have enough allies, then a problem may not be worth tackling or needs a different approach. HAI has not played a prominent role in the major scandals of the industry in the past 10 years. Now we have heaps of books on the misdeeds of industry in the US, Canada, Australia, Holland and Belgium. But that



doesn't mean HAI is missing the boat, HAI is busy at an earlier stage of incubation on these things.

HAI is a catalyst. It brings together people who need mutual support and who do better with it. Look at the way Barbara [Mintzes], Joel [Lexchin], Charles [Medawar], Peter [Mansfield] and I have worked on drug promotion. Five people having a disproportionate effect in relation to drug promotion and direct-to-consumer advertising (DTCA). That's HAI.

In the future, I sense that if there are areas which are not really recognised by people then HAI will find ways to get them discussed publicly. It will be more of the same, but also different each time. That's the point, the flexibility. If you have a flexible agenda that makes it much easier to deal with things as they arise.

1984

- Stanley Adams, jailed for revealing an illegal price-fixing scheme by vitamin manufacturer Hoffmann-LaRoche, publishes *Roche versus Adams*, which describes his bitter experience.
- Charles Medawar's book, *The wrong kind of medicine?*, examines more than 800 non-essential products on the market in the UK; a second publication by Medawar, *Drugs and World Health*, looks at similar problems in other countries.
- International protest helps prevent a law from being introduced in the US which would have allowed exports of pharmaceutical products not approved by the country's own Food and Drug Administration.
- India begins preparation of a national drug policy.
- The UN Centre on Transnational Corporations publishes a report on the pharmaceutical industry in developing countries.
- The first version of the *UN Consolidated List of Products which were banned, withdrawn, severely restricted or not approved* is published.
- Germany cancels the registration of 43 combination products containing aspirin.

1985

- The WHO sponsors the Nairobi Conference of Experts to discuss the importance of rational drug use.
- HAI network in East and Central Africa is launched.
- Ciba-Geigy meets with its critics, including HAI, to discuss its anti-arthritic drugs, phenylbutazone and oxyphenbutazone. A month later, Ciba announces it will withdraw oxyphenbutazone worldwide and recommend a restricted use for phenylbutazone.
- HAI submits a position paper to the European Parliament on the export of drugs to developing countries.
- HAI groups in Canada form a national network.
- The Dag Hammarskjöld Foundation holds an international seminar "Another Development in Pharmaceuticals".
- An international campaign is launched criticising the promotion of cyproheptadine and pizotifen as appetite stimulants.
- Wemos relaunches its campaign on Organon's marketing of anabolic steroids after research shows that the company has not implemented the changes agreed in 1983.
- Francis Rolt's book, *Pills, Policies and Profits* analyses the impact of the Bangladesh national drug policy and concludes that there have been some impressive results.
- HAI and six other organisations join forces in a Coalition Against Dangerous Exports to press the European Commission to introduce strict export controls; the Coalition publishes Andrew Chetley's report, *Cleared for Export*.
- BUKO Pharma-Kampagne launches a campaign against Hoechst.
- Jennifer Amery and Roberto Lopez produce a book on the irrational use of pharmaceuticals in Peru entitled *Medicamentos en el Perú: Comercialización y consumo*.
- Ciba-Geigy announces that it will stop the supply of all oral antidiarrhoeals containing clioquinol by the end of March 1985.
- Indonesia bans 90 combination products.
- Hoechst announces that it will withdraw all nomifensine products, in part due to the publicity generated by the BUKO campaign.

Oscar Lanza, Coordinator, AIS/HAI Bolivia, La Paz, Bolivia

“We have to stay loyal to our original commitments”

“The most significant thing HAI has accomplished in its history is bringing out national and international public concerns on access to essential medicines and the rational use of medicines, because in a world that claims to be ‘civilised’, every three seconds a child dies due to poverty-related diseases, which are easily preventable. Each year 17 million people die due to infectious diseases and 33 million people living with AIDS cannot get access to medicines due to unfair trade rules. In addition, eight million human beings suffer the consequences of tuberculosis, malaria, Chagas disease, among others.

In 1985 a small group of Bolivian health workers and professionals decided to join HAI’s efforts, since we shared the HAI philosophy, objectives and strategies, promoting integrated primary health care (PHC) and Dr. Mahler’s proposals [former WHO Director-General]. Since then, we have been loyal to HAI’s original principles that ‘the best medicine in the world consists of access to appropriate nutrition, pure water, sanitation, education and information’.

The role of HAI has changed due to the new international scenario, the trade agreements and their impact on people’s health and on access

to essential medicines. HAI now faces new challenges in the present globalised world. HAI has repeatedly claimed that health should prevail over commercial interests. The role of HAI has become increasingly important and even crucial in the era of ‘free trade’. The future means new challenges for HAI; however we have to stay loyal to our original commitments: promote an appropriate and acceptable living standard for all human beings, wherein the right to health and access to essential medicines will be respected and wherein pure water, adequate nutrition, sanitation and education are accessible in this civilised world”.

Albert Petersen, Country focal point and Chair of the Ecumenical Pharmaceutical Network, DIFAM [German Institute for Medical Mission], Tuebingen, Germany

“The pricing studies are important”

“The pricing studies done by HAI are very important. The results supported a lot of local activities in the South and in the North as well. Knowing how Big Pharma is influencing health negatively due to high prices is extremely important.

And in addition, the four surveys about the products German companies are offering in the South done by BUKO as a HAI member

have guided and supported lots of our own activities too.

I became involved in HAI to get more linked to consumers worldwide, to learn from them, from their achievements and from their challenges. Networking is a key issue today; we have to learn from each other, we have to support each other”.

1986

- Work begins on a national drug policy in The Philippines.
- Action for Rational Drugs in Asia (ARDA) is launched.
- Deadline announced for claims of damage caused by the Dalkon Shield IUD.
- Merck Sharp & Dohme announces that it has stopped all promotion of cyproheptadine as an appetite stimulant.
- Several manufacturers in the US announce plan to withdraw IUDs in the face of growing concern about their safety and increased litigation.
- WHO’s Revised Drug Strategy is adopted.
- HAI publishes its *Problem Drugs* pack (in three languages), and a report by Dexter Tiranti called *The Bangladesh Example: Four Years On*.
- Forty-five representatives from 27 countries attend the first HAI international conference in Bogève, France.
- Several countries withdraw aspirin products for children.
- The Dag Hammarskjöld publication, *Development Dialogue*, features an extensive report on pharmaceuticals.
- Irish MEP Mary Banotti produces a tough report on European exports which the European Parliament approves.
- HAI groups in the US form a network.
- The International Society of Drug Bulletins is founded.
- Following the appeal by the pharmaceutical industry in India which resulted in a stay order on the ban on high-dose oestrogen/progestogen drugs, the Indian Supreme Court calls for a public hearing to decide whether the ban should be lifted.
- IOCU publishes *Adverse effects: Women and the pharmaceutical industry*, edited by Kathleen McDonnell.
- The Voluntary Health Association of India publishes *Banned and Bannable Drugs* and a set of six posters encouraging rational drug use; People’s Science Movement in Kerala, India publishes *Dear Doctor, Drug Information Pack*.
- Nine drugs are banned in Malaysia; 220 irrational drugs are banned in Peru.
- *New Internationalist* magazine runs a special feature issue on pharmaceuticals.
- Six DES daughters in the Netherlands bring a lawsuit against makers of the drug.

A conversation with Catherine Hodgkin

“A magical mix”

CATHERINE HODGKIN WORKED AS COORDINATOR OF HAI EUROPE FROM 1986 UNTIL 1996. SHE STARTED AS THE HEALTH PROJECT OFFICER FOR THE INTERNATIONAL ORGANIZATION OF CONSUMERS UNIONS (IOCU). SOON SHE FOUND HERSELF MOVING TO MAKESHIFT OFFICES, WITH NO STAFF AND ONLY A TELEPHONE AND FAX MACHINE. DURING HER YEARS AS COORDINATOR, SHE HELPED BUILD THE FLEDGLING NETWORK INTO AN IMPORTANT FORCE WITHIN INTERNATIONAL DRUG POLICY. STILL IN TOUCH WITH MANY HAI MEMBERS, CATHERINE IS NOW DIRECTOR OF DEVELOPMENT POLICY AND PRACTICE AT THE ROYAL TROPICAL INSTITUTE (KIT) IN AMSTERDAM.

WHAT WERE SOME OF HAI'S MOST IMPORTANT MOMENTS?

The publication of *Problem Drugs* in 1986 was very important. It gave HAI incredible credibility. The industry got very cross about it, but they couldn't challenge it, it was well researched, referenced and written. Many respected pharmacologists, doctors, health professionals, development experts and academics agreed with it and endorsed it. After it was published, it wasn't easy to refer to the author and HAI as a bunch of crazy activists.

Another moment was the WHO Nairobi meeting [on rational drug use] that was held just before I came in. That was when WHO really started to see the importance of the rational use of drugs. There were a number of reasons why it was so important. It started an important discussion on the idea that drug use was much more than just getting drugs to people. Before the meeting, the emphasis was largely on

logistics and supply. But drugs were being badly used. There was lots of irrational use and appalling promotion and these were enormous problems. Nairobi was the first time that WHO really emphasised that rational drug use was important, even though the Essential Drugs Concept was already several years old.

Nairobi was the first international meeting where HAI was powerful as a lobby group. Industry representatives were very frustrated with the recognition given to consumer representatives. (HAI members had been invited through IOCU.) There was fighting in the corridors about it! People then really had to make room for HAI and listen to it. At the meeting, a video was shown by Oxfam with the same ideas as those in Diana Melrose's book *Bitter Pills*. The industry was pictured as the villain in a number of scenes in which drug reps were depicted waiting outside hospitals in Latin America. The images were strong and the video was

confrontational. The industry was furious and absolutely alarmed at the power of the message that came across in Nairobi.

The main outcome of the meeting was that there were a number of expert committees set up and HAI had a place on them. One of the first things I had to do when I started was organise HAI representation on those committees. That was when the Ethical Criteria [on drug promotion] and the Guidelines for National Drug Policies were being drafted. HAI could nominate people to take part in the committees and it was helping to set policy. We knew it was very important and that we had an opportunity to affect the shape of drug policy for the future.

You should read the Heritage Foundation review of HAI that came out around the time of the Nairobi meeting. It's classic. They were convinced we were funded from Moscow. They thought it was a huge,

well-funded organisation with a large staff and 'cells' all over the world. We really laughed and loved to cite this report as we tried to survive with minimal staff and minimal funds.

My first year at IOCU, at the HAI annual meeting in Bielefeld, everyone said they wanted a summer school. That school was important for a lot of people active in HAI during the following ten years. It was a launching pad for many of the people who became key in the HAI Europe campaigns carried out in the following years: BUKO, Wemos, Medico, Declaration de Berne and the French groups were all there. It was a big thing for young European activists. The nice thing and maybe the most powerful thing about HAI could be seen there. The program had an incredible array of really great teachers. They all came for free and worked overtime talking about things like drug regulation and drug safety. People were working all day and all night. It was the first time many people had worked with a computer! Wilbert [Bannenberg] persuaded me to buy one with my own money so that we would have enough – and of course contributed his own as well. We came in a van with two computers (and a generous supply of booze) and people

waited hours to use them and often booked them until deep in the night. Suddenly people had insight into what you could do with a database – it was too early for Internet and email. In addition, it gave people a pressure cooker course on the technical aspects of rational drug use.

Dr. Mahler, who was then Director General of WHO, was open in his support of and admiration for much of what HAI was doing, as was Ernst Lauridsen who was director of the WHO Drug Action Programme. These people were extremely important to us. They were fans and let it be known. At meetings, they would stop and talk to us. They invited us to breakfast meetings. That helped to establish the power of HAI as a lobbyist at WHO. Some of Dr. Mahler's speeches were uncompromising in their criticism of unethical marketing and inequities in health. The speeches could have been written by HAI activists!

The launch of *Problem Drugs*, *Promoting Health or Pushing Drugs* and *Med-Sense*: those three publications all symbolise high spots for me. But it is hard to say what the most important moments and campaigns were. I think that that is different depending on what your main interests were.

The 1992 Geneva meeting was a good international meeting. Some would say HAI's work around the Bamako Initiative was really important for its impact on international policy. *Problem Drugs* was an extremely useful and important tool for promoting what HAI was doing. The relationship with ISDB [International Society of Drug Bulletins] was very important as well. The Banotti Report in the European Parliament was also very important for HAI Europe. For people working primarily at national level, other milestones were probably much more important – for instance, the launch of the Bangladesh National Drug Policy or the Philippines drug policy and generic policy was very crucial.

HOW DID YOU GET STARTED IN HAI?

I started working there at the end of 1986. It was just me and Gina Wenberg, who worked as a secretary. I took over from Virginia Beardshaw who was the first coordinator working in The Hague. Bala was recruited at about the same time in Penang and as a much respected UN expert he brought a great deal of credibility and tremendous knowledge with him. We had a room in the IOCU office in the attic. HAI existed as a network and the secretariat was an IOCU project. Funding had

“People really had to make room for HAI and listen to it”

been obtained from SIDA and NORAD to run the project.

The HAI Network was in a period of exponential growth and quite early on there was a difference of opinion with IOCU about how far and how fast HAI should develop. One of IOCU's main priorities was work on their European patient rights campaign, not just medicines, but this work wasn't funded and there was both funding and a great deal of work to do for HAI. In the end, there was a clear deciding moment: IOCU wanted me to concentrate on the European consumer agenda – the HAI Network wanted me to concentrate on their funded work programme. One week-end there was a meeting at Wemos, with Andrew Herxheimer, Charles Medawar, myself, Andy Chetley, Janita Janssen and others and we had to decide what to do. We decided that the best thing was to go. Gina decided to stay in The Hague. At first, it was me on my own, but a number of people were incredibly supportive, people like Wilbert Bannenberg making sure that HAI survived. We didn't think about the situation as a crisis, but we didn't really have a place to go! We were uncertain about the project money too, though IOCU cooperated and thought that it was best if

the HAI project continued independently and transferred all remaining project funds to HAI.

And very soon there was Rose [de Groot] as well. She was a late applicant for the post and I was feeling gloomy about finding someone suitable. Wilbert and I interviewed her in the marble entry hall of the Royal Tropical Institute [in Amsterdam] as we didn't have an office. Soon afterwards we moved to Wilbert's attic and we never looked back! Not long after that we moved to the Jacob van Lennepkade and then Ellen, Barbara and Babet all joined within a fairly short space of time and that felt like a great team.

WAS HAI THE FIRST ORGANIZATION OF ITS KIND?

No, IBFAN [International Baby Food Action Network] was already there. We were learning from their successes to some extent. It had different goals but the model was quite similar. And there was also PAN [Pesticides Action Network].

HOW WAS THE WORK DIVIDED BETWEEN THE OFFICES?

The division of tasks was done more by consensus than official agreement. It was clear that Bala did *HAI News* and

was an important leader and figure. Elly Kerkvliet coordinated the groups in Latin America. Although he wasn't yet coordinator, Roberto [Lopez] was already active in the network in Peru. But the clear political advocacy push was coordinated in Europe, at least as far as the international policy agenda was concerned.

One of the big changes in the coordinator's job between then and now was that I coordinated active groups and did not run any projects. That is something that started in the last few years. In general, we didn't have specific big projects apart from joint publications and of course the major lobby events. We pushed, suggested, supported and coordinated people but the projects were mainly done by the groups themselves. It was coordination of the groups that were active and that gradually changed.

WHAT WERE THINGS LIKE AT HAI WHEN YOU WERE THERE?

In those days we really believed we could conquer things. There was an optimism in some activities that made them work. The amount of work being done by just a few people was unbelievable! It was probably not sustainable and some things had to

become more institutionalised. For instance, we didn't really address issues of network governance because everything seemed to work on trust and ideas. This is fine but in an expanding network you also need to look forward. We had to become more realistic about what we could do and we really needed to raise money for campaigns and continuity. In the early days, HAI was like a bubble that could be pricked, but we believed in it and managed to get away without anyone pricking it. Charles [Medawar] once referred to HAI as a castle with huge ramparts but only a very small army behind the ramparts. “Keep on moving around”, he said, “and you give the impression that you are a big force”.

DID YOU EVER THINK HAI WON'T MAKE IT?

There were lots of moments when we thought that the industry was too strong, the economic forces too big, and our own organisation too limited. Sometimes it was depressing to be the 'token' consumer at yet another meeting. (We were sometimes invited just to shut us up and not to give any space to our ideas.) But what HAI does manage to do best is bring together academics, policy makers, and activists in a magi-

cal mix. It's a combination of activism, moral high ground, good science and an enormous amount of work. It is very motivating and that energy pulls a lot of people along.

There was a constant and very understandable pressure mainly from groups in the South saying that maybe HAI's focus was too narrow. That it should not only be looking at drug issues but also at basic health issues. That's hard because what we ultimately wanted to achieve was not always what HAI could do best. We felt that HAI had to focus and could only be powerful because it was focused. But some of the groups in the South felt that this made pharmaceuticals too central to the wider health goals. Now I think the People's Health Movement is taking up some of that and working with those who wanted to make HAI broader.

The international meeting in Geneva in 1992 felt very powerful. There was also a great meeting in Penang a bit earlier. HAI felt like a rock solid thing. We never had a very strong idea of where we wanted to go to as an organisation. We knew what we wanted to change, but the staff didn't have a vision of what HAI would look like in



five years. We were thinking more about the problems and campaigns and getting money for them. We weren't thinking about pensions for the staff or institution building. We knew there had to be some institutional, long-term planning, but we weren't doing it then – maybe not enough.

DOES HAI STILL HAVE A ROLE TO PLAY AGAINST INDUSTRY?

I think HAI is still really important as a counterweight to industry and to commercial interests. Consumers still need a voice which is advocating health for people above profits for companies. The HAI mix of science and activism remains really important. You can't compete with the pharmaceutical industry on money.

WHERE SHOULD HAI FOCUS ITS ATTENTION IN THE FUTURE?

HIV/AIDS has made a big difference to HAI's work. The

fact that you could no longer say that 95% of the world's health problems can be solved with drugs costing about US\$1. The advent of HIV/AIDS meant that the Essential Drugs Concept was no longer an obviously affordable answer to access problems. It blurred boundaries a bit and put international attention back on how to buy these drugs and get them to people. I think HAI's response to that has not been heard enough or been clear enough. The question is: how to get drugs properly used and make them affordable.

When Dr. Mahler retired from WHO, I met with him and Dr. Cohen. They said to me "HAI is doing really great work, but you have to pay more attention to new drugs, how to make new drugs available to poor people". We were advocating essential drugs, nearly all of which were generic drugs with a long track record and highly affordable, but what they said turned out to be prophetic. I think HAI should not forget the critical issues relating to rational use. That has suffered from the health concerns of the last few years but it is still as important as ever. Recent articles on promotion activity in Holland show that very little has actually changed.

The advent of information technology has changed the job of the HAI network. We used to send out photocopies of medical journal articles on a monthly basis. People were dependent on European organisations to get information. Now people don't join HAI to get information, now they get it from many different sources. When I think back, we used to send messages by telex, the fax was a real revolution! So much networking was new at the beginning of HAI. There was not that much international networking being done. People were keen to get information and moral support from HAI. Maybe more people are involved in those kinds of issues now but I doubt if they get the same feeling of belonging that they used to get with HAI in the early days. Globalisation has brought the issues and the information potentially much closer to many people – but at the same time networking in cyberspace can be quite impersonal.

DID YOU ENJOY YOUR TIME AS COORDINATOR OF HAI EUROPE?

It was great to work at HAI. Not always of course: low salary, no pension in the beginning and lots of worries about continuity of funding. Looking back, it's hard to

imagine that I could have liked those very early days working in the attic with Rose. Thank God for Rose! But I think we were very happy and there was a strong team spirit.

When things were going well and on the up, and the team became bigger, it was just great. My husband once said to me, "You work with brilliant people. The people who drop by the house are so inspiring. You don't know that most people work with boring people every day". I'm not trying to make it rosier than it was. At its best it was really inspiring to work there. At its worst, it was the agony of not knowing about funding and staffing. That's why I left in the end. I felt that somebody else was needed to put in the next round of energy and move HAI forward. I wanted to secure new funding for four more years and then go. I felt HAI Europe needed someone new, a new phase. I heard myself saying "Yes, but we have done that" once too often. I wasn't tired of the issues, the network or the people but I wanted some time to study and I thought HAI needed movement – new visions and new ideas.

1987

- HAI takes part in a WHO symposium on steroid contraceptives.
- BUKO publishes a report on Hoechst called *Hoechst: A cause of illness?*
- HAI summer school is held in Sweden, attended by 45 people from 15 countries.
- Berne Declaration launches *Medi-minus* to inform Swiss doctors on rational prescribing. Berne Declaration also launches a series of publications on the activities of Swiss companies in developing countries.
- HAI launches an international campaign for the removal of antidiarrhoeal products which contain antibiotics: HAI publishes the report, *Antibiotics: The wrong drugs for diarrhoea*.
- A new drug policy is introduced in The Philippines.
- The Thai Drug Study Group launches a major campaign to have dipyrone withdrawn from the Thai market.
- Health Action Information Network (HAIN) publishes a new edition of its report, *Banned, withdrawn and restricted drugs*, which lists products that are supposed to have been removed from the market in The Philippines.
- The Bamako Initiative is proposed.
- Wemos publishes a new report on Organon and anabolic steroids.
- The first regional meeting of AIS groups in Latin America is held.
- Suprol (suprofen) is withdrawn worldwide.
- Hoechst announces that it will withdraw combination products containing dipyrone in Germany, but not in the rest of the world.
- Parke-Davis announces it will withdraw its streptomycin and chloramphenicol antidiarrhoeal product in response to pressure from MaLAM.
- Combination products containing dipyrone are banned in Pakistan, and another 605 drugs are deregistered as being harmful or ineffective; 12 categories of irrational and harmful drugs are banned in India.
- Sandoz withdraws a combination antidiarrhoeal containing broxyquinoline and tetracycline following pressure from the Berne Declaration Group.
- First ARDA meeting is held in April.

1988

- WHO publishes the *Ethical criteria for medicinal drug promotion* and urges all member states to take measures to ensure that drug promotion supports the aim of improving health care through the rational use of drugs.
- AIS groups in Latin America produce the report *Medicamentos, los casos de Bolivia, Brasil, Chile y Peru*.
- A HAI international meeting in The Philippines brings together 44 participants from 25 countries.
- The first European DES conference is held in Brussels.
- HAI/ARDA holds an international consultation on rational drugs and medical/pharmacy education in The Philippines; the international network of Educators for Rational Drug Use (ERDU) is created.
- ARDA groups focus on the use of medicines by children.
- Sidney Wolfe's book, *Worst Pills, Best Pills*, focuses on medicines for the elderly.
- The Schering Action Network is formed.
- Michael Tan's book, *Dying for Drugs*, looks at the use of pharmaceuticals in The Philippines.
- Pakistan bans combination products containing analgesics with barbiturates and cancels the registration of the painkiller Optalidon.
- After six years of intensive effort, HAI groups in India welcome a government ban on high-dose oestrogen/progestogen drugs.
- The lawsuit brought by Dutch DES daughters is rejected by the court because the women cannot prove which manufacturer produced the DES taken by their mothers.

1989

- Ernst Lauridsen resigns from the WHO Action Programme on Essential Drugs in protest of the ways in which the aims of the Revised Drug Strategy are being "watered down".
- HAI co-sponsors an international consultation on the Bamako Initiative in Sierra Leone.
- The People's Health Network is established.
- AIS begins a campaign on antidiarrhoeals.
- IOCU publishes the English translation of Olle Hansson's book, *Inside Ciba-Geigy*.
- High-dose contraceptive pills are banned in South Korea, following campaign efforts by the Citizen's Alliance for Consumer Protection of Korea.
- Ciba-Geigy withdraws nikethamide products worldwide, following pressure from MaLAM.
- Wellcome withdraws its kaolin/pectin antidiarrhoeal, ADM, worldwide, following a UK TV documentary drawing on the experience of HAI groups campaigning against inappropriate antidiarrhoeals.
- *Dipyrone: a drug no one needs* is published by HAI and BUKO Pharma-Kampagne.
- Wemos' Women and Pharmaceuticals project publishes *Fertile market: women, menstruation and the medical industry* by Ivan Wolffers, Anita Hardon and Janita Janssen.

Interview with Ellen 't Hoen

“HAI is a group of activists”

ELLEN 'T HOEN HAS SPENT MOST OF HER CAREER CAMPAIGNING ON HEALTH AND MEDICINE ISSUES. AS ONE OF THE FOUNDERS OF DES ACTION IN THE NETHERLANDS, SHE HELPED START A EUROPEAN GROUP THAT INFORMED AND ADVOCATED ON BEHALF OF WOMEN INJURED BY THIS DRUG. SHE LATER MOVED TO THE HAI EUROPE OFFICE WHERE SHE LED ITS CAMPAIGNING EFFORTS FOR YEARS. IN 1999, SHE JOINED MÉDECINS SANS FRONTIÈRES' INTERNATIONAL CAMPAIGN TO INCREASE ACCESS TO ESSENTIAL MEDICINES. BELOW SHE RELATES WHY SHE GOT INVOLVED IN MEDICINE POLICY WORK AND THE REASON WHY ACTION IS A CRUCIAL PART OF HAI'S NAME AND IDENTITY.

HOW DID YOU BECOME INVOLVED IN HAI?

You can thank the DES-producing pharmaceutical companies for that! When Anita Direcks and I set up DES Action in the Netherlands, we thought we were dealing with a one-off problem. We really thought, yes, this is unfortunate for us and other women affected by DES, but we thought it was a limited problem.

But that belief didn't last too long. Once we started to understand how the DES situation had happened, I mean how much was already known about the drug while it was still being prescribed and kept on the market. You had to start asking: how could this happen? Who is responsible? Where were the doctors? Shouldn't they have known? Where are the regulators?

We were looking at one bad drug but it was a speed immersion course in pharmaceutical politics. All of that brought me to HAI. I wanted

to learn more about how this could happen. Through HAI I met people from the women's health book collective, Sidney Wolfe in the US consumer movement and started reading their stuff. Someone also told me to read the work of Ralph Nader. I also became familiar with the work of Dianna Melrose, Andy Chetley, Andrew Herxheimer, Graham Dukes, Charles Medawar and others who were writing on the problems caused by pharmaceuticals.

DES Action started becoming more international. We got in touch with groups in other countries and helped set up DES offices in other European countries. We did it to find other women suffering from the effects of DES and we discovered that women in developing countries were still taking DES for the same things. We saw that this was a story that was still going on.

In 1984, I think, there was a big conference on reproductive rights organised by the

Women's Global Network for Reproductive Rights in Amsterdam. That was a big moment. I met all kinds of people there like Anita Hardon, Janita Janssen, Carla Marselis, Mira Shiva, Amparo Claro, all women I learned a tremendous amount from. I learned the power of organising. That was what was missing in the DES problem. Everything was known about the drug, but nothing happened. It was lacking action. This all became clear in about 30 seconds!

So DES Action became a member of HAI. Other HAI groups starting using some of our material and we were able to learn a lot from the other members but also expand our outreach.

Something I really remember was the HAI summer school. That summer in Sweden we were taught about things like basic pharmacology. I remember Andrew's course on pharmacokinetics and what the half life of a drug is, all of

the technical stuff. I still use that knowledge today to bluff my way through the pharmaceutical world!

I joined HAI when Catherine [Hodgkin] went on maternity leave with her youngest child, Emma. I was hired to be a campaigner. Perhaps the money I had raised at DES Action acted as an incentive to hire me!

HOW IMPORTANT WAS CAMPAIGNING TO HAI?

HAI is a group of activists, doers. We were using expertise and people sitting in different places. It was a real network. HAI Europe had a very small office. People from the network took part in different ways, some even behind the scenes; they all contributed to the work from the work places where they sat.

HAI's early campaigning work was based on the double standards used in marketing and the lousy things that were being sold in developing countries. This is what united the group. Slowly HAI realized that the problem wasn't just this bad drug or that one, it was that there was a need for better drugs in general and better policy about medicines. HAI also started to see that governments had a real responsibility to make decent

policy about drugs. So HAI's campaigning changed during the early years as we started to have different goals about what we wanted to accomplish.

When I joined the HAI office, the network was already changing from campaigning against problem drugs to campaigning on medicine policy. That is what brought HAI to the World Health Assemblies in Geneva, for example. We wanted to work on policy and protect the Essential Drugs Concept which was constantly under attack.

Our campaigning work linked international drug policy work to the work national groups were doing on things like national drug policies. And things like strong national drug policies helped our efforts on international policy.

WHAT ARE SOME OF THE KEY CAMPAIGNS YOU REMEMBER?

The consumer health movement missed the boat on the formation of the World Trade Organization during the GATT [General Agreements on Tariffs and Trade]. That's when the new rules on patenting, pricing actually, were drawn up. We weren't geared up for it and didn't have the capacity

to do it. Plus, a lot of the key meetings were done secretly. But once it became clear what the consequences would be, it was late. At the same time, it was also hard to campaign until the consequences became clear and the AIDS pandemic did that. The World Council of Churches and HAI organised some meetings on the GATT and access to medicines in the early '90s. HAI and BUKO held a meeting on the WTO and GATT and the consequences for consumers of medicines in Bielefeld in 1996 too, which in fact kick started the campaigning on the WTO.

Another important one was the secrecy campaign, but that was really led by Charles [Medawar] and Social Audit. We see that the need for greater openness is talked about now. That was a very important campaign. We said that drug regulation is not there for the drug companies but for the health and safety of people. Now with all kinds of new technology available, things that were considered state secrets back then can now be found on the Internet!

I think the Uppsala statement made at the meeting sponsored by the Dag Hammarskjöld Foundation was one of the most beautiful documents



“I learned the power of organizing”

amazing people and bring them together to reach a goal.

IS THERE STILL A CAMPAIGNING ROLE FOR HAI TO PLAY?

Yes, now more than ever! There are opportunities again. For a time, everyone was saying, just leave it to market forces, but people see that hasn't worked and the mood is changing now. It's obvious that the market won't deliver what everyone needs. As a result of globalisation, decision-making is moving further and further away from people. HAI has an important role to influence decision-making and bring people's concerns to the forefront. Now we need a next generation of HAI. I remember

we ever did. It is so small and to the point. Graham Dukes played a major role in that. He's a wonderful writer and a key activist, although he wouldn't describe himself perhaps that way. That is the story of HAI. It's not an organisation. It's about people who are passionate about something. They give their time, knowledge, experience and even the power they have. So you get these

someone once saying to me “So now, you're the next generation” and that was 20 years ago! The NGO world has become an industry. Smart, committed people can find a job, fairly well paid, at brand name NGOs. That may be why it's hard to find people to join the network today. But I have a feeling that may change again. People are more in activist mode now. Before September 11th that feeling was very strong, people were out in the streets, demanding, complaining. Things have changed since then, but it's still in the air.

Julien Reinhard,

Déclaration de Berne (Berne Declaration), Lausanne, Switzerland

“A respected interlocutor”

“HAI has managed to build and maintain a network of independent, competent and dedicated organisations and individuals. Over the past 25 years, HAI has become a respected interlocutor for governments, intergovernmental organisations and the specialised public and succeeded in bringing its concerns and ideas to the top of the political agenda (e.g.

rational use of medicines, unethical medicine promotion, etc.). In a field like health, and in particular, pharmaceutical policy, where it is not easy to find people to act publicly against huge financial and corporate interests, and where there is such an imbalance of power, this is a great achievement”.

1990

- The Generics Act comes into effect in The Philippines.
- In cooperation with BUKO Pharma-Kampagne and Declaration of Berne, HAI publishes a report on unhealthy exports by German and Swiss pharmaceutical companies; it also publishes *Peddling Placebos*, a report on inappropriate cough and cold preparations written by Andy Chetley.
- Janssen announces the withdrawal of the paediatric drops formulation of Imodium (loperamide) following a UK TV documentary which draws on the experience of HAI groups and physicians in Pakistan.
- The Olle Hansson Award is given to three Latin American AIS activists: Jose Augusto de Barros (Brazil), Arturo Lomeli (Mexico) and Roberto Lopez (Peru).
- DES Action holds a symposium to raise awareness of the DES issue among health professionals and policy makers and to examine current pharmaceutical policy in light of the history of DES use and the consequences of widespread exposure.
- Wemos and HAI produce a Women & Pharmaceuticals bulletin on DES, injectables, implants, the abortion pill and anti-fertility ‘vaccines’ to coincide with the 6th International Women and Health conference held in Manila.
- Andrew Chetley publishes *A healthy business? World Health and the pharmaceutical industry*.
- AIS publishes a study on tranquiliser use by women in Uruguay.

1991

- Indonesia announces the withdrawal of 282 hazardous drugs.
- Germany bans all dipyrone combination products.
- Wemos/HAI Women & Pharmaceuticals project holds an international seminar highlighting women's perspectives on fertility-regulating technologies. International guidelines for appropriate distribution and use of contraceptives are drafted based on the meeting's discussions.
- The second AIS networking meeting is held in Montevideo.
- A seminar on rational drug use in Southern and Eastern Africa, organised by HAI Europe and contacts in Africa, is held in Harare.
- HAI groups in Finland carry out an extensive study on Norplant, finding it very difficult to obtain data on the contraceptive from the regulatory authorities.
- PIMED conducts a survey of advertisements appearing in four medical journals edited in France but sold in Africa. It finds 40% of the advertisements provide different information from that provided in VIDAL, the guide for drug prescription in France.
- *La Revue Prescrire* starts a campaign urging doctors to stop seeing medical representatives for one year and to become more conscious of the source of the information they receive.
- The Wemos Pharma Group publishes its study *Exposed: Deadly Exports: The story of European Community exports of banned or withdrawn drugs to the Third World*.
- HAI Europe releases *The provision and use of drugs in developing countries*, edited by Anita Hardon.
- AIS Nicaragua publishes the first edition of a handbook called *Buscando Remedio* [Seeking the best remedy]. Its aim is to provide the country's health professionals with a user-friendly manual giving guidance on the dispensation of basic care and the appropriate use of a limited list of essential drugs.

1992

- HAI holds its international meeting in Geneva directly before the start of the World Health Assembly.
- HAI launches an international campaign against secrecy in medicines control. Many HAI groups take up action to improve transparency within national regulatory agencies and at the European level.
- HAI highlights the problems caused by drug promotion in *Promoting health or pushing drugs? A critical examination of marketing of pharmaceuticals*. The publication appears after an international survey undertaken by members of the network suggests that the WHO Ethical Criteria have had minimal impact on the standard of promotion worldwide.
- *Primary health care and drugs: Global action towards rational drug use* is published by HAI and BUKO Pharma-Kampagne. It examines the relationship between rational drug use and the provision of primary health care.
- HAI promotes more rational drug use in the Baltic States during a project carried out jointly with the Latvian Academy of Medicine and Remedia, a foundation promoting rational drug use in Lithuania. The report *Medicines and Independence: Towards more rational drug use in the Baltic States* which includes discussions from a meeting held as part of the project is published later.
- HAI Asia-Pacific reports on medicines used to treat children with diarrhoea or non-severe respiratory infections. The study is carried out by ARDA and groups from Malaysia, Korea, Indonesia, The Philippines, Bangladesh, Pakistan and Sri Lanka.
- Groups from AIS start a campaign on anti-diarrhoeals and children.
- Social Audit raises questions on the safety of medicines in Charles Medawar's book *Power and Dependence*.
- The Dutch Supreme Court overrules lower courts' decisions on the DES daughters' lawsuit, paving the way for liability suits against the manufacturers of DES. In its ruling, the court states that each company that sold DES in the Netherlands can be held liable for the complete damage the women have suffered.
- HAI Europe launches *Med-Sense*, a packet of drug information leaflets packaged in a pill box. Over time it will be translated into many languages.
- The Swiss Drug Information Centre opens a national telephone line so that consumers can ask a doctor or pharmacist questions about medicines.

1993

- HAI launches the second edition of *Problem Drugs* in more than 20 countries on six continents. The publication is translated into numerous languages.
- Judith Richter writes *Vaccination against pregnancy: miracle or menace*.
- HAI groups in Finland study the advertising of over-the-counter drugs. After analysing 89 advertisements appearing in the largest newspapers and magazines, they find that two-thirds of the advertisements lack the information required under Finnish law.
- The UK's National Consumer Council recommends changes in the way drugs are regulated in the UK and raises concerns about conflicts of interest within regulatory agencies.
- In June, the Arab Resource Collective organises a workshop for rational drug use for countries in the Middle East.
- In response to public pressure, the US FDA withdraws approval of Sandoz's drug Parlodel (bromocriptine) as a lactation suppressant. Sandoz is the only company not to voluntarily remove the indication from its product. HAI Europe urges its contacts to call for this indication to be withdrawn in other countries where the drug is still sold for this use.
- Women's Health Action Foundation publishes *Norplant: Under Her Skin*.
- PIMED publishes a study on what happens to unused drugs in various European countries.

An interview with Ilze Aizsilniece “HAI was a university for me”

ILZE AIZSILNIECE BEGAN WORKING WITH HAI EUROPE IN 1991 AND PLAYED A KEY ROLE IN ITS ACTIVITIES CARRIED OUT IN THE BALTIC STATES AND OTHER AREAS OF THE FORMER SOVIET UNION FOR MANY YEARS. TODAY SHE REMAINS ACTIVE IN HAI AND WORKS AS A GENERAL PRACTITIONER IN RIGA, LATVIA. SHE ALSO DOES SOME CONSULTANCY WORK FOR THE WORLD BANK AND THE WHO.

HOW DID YOU BECOME ACTIVE IN HAI?

I first got involved with HAI when I was coordinating activities of the Latvian Medical Students Association with the Turkish Medical Students Association. We had a meeting in Riga and talked about different problems in health care, also pharmaceuticals. Yunus Emre Kocabasoglu [the leader of the Turkish Medical Students group] asked if I wanted to go to a HAI meeting. That was held in 1991 in Woudschoten, Holland. It was the first time I met people from HAI. Until 1991 we had very different problems in Latvia, mostly drug shortages. But then things changed and there were new problems, like a lot of drug promotion. The concept of rational drug use was a new idea.

From 1993 through 1994, we did the project “Towards rational drug use in the Baltic States” with HAI Europe. We had a number of seminars attended by people from different institutions and NGOs. The same people who were there are now working in

rational drug use in the country's institutions. This project had a great impact on people who are now working on national drug policy in those countries.

We had very good materials developed during the project on the rational use of drugs and drug promotion. It helped us to develop good cooperation with the Latvian media. Consumer education was a big component of the project. After a few years, we also did a voluntary project with the ministry of education. Teachers giving health education programs in primary and secondary schools could teach in general about the problems caused by drugs. They used *Med-Sense* which was translated into Latvian and Russian. Actually it was translated into all three Baltic country languages plus Russian. A group in Poland also translated *Med-Sense*.

Problem Drugs was also translated into Russian. Now it is read by many people in Russia and other Russian-speaking countries. It was put up on the web two or three

years ago. A consumer institute in Russia did it. We sent them all the files.

WHAT DID HAI PROVIDE?

HAI was very important for me. As a general practitioner, I was facing quite a number of problems. The main problem was the medical education given under the former Soviet Union system. Only brand names were used, no one knew about INNs [International Nonproprietary Names]. They didn't teach us about it in medical school. Through HAI, I learned a lot about pharmaceuticals.

Drug promotion in our country started in 1992, and I really disliked what it was doing. HAI was consumer and patient-centred. They showed how we could reach consumers, how we could have dialogue with consumers about drug issues.

WHAT HAPPENED AFTER THE BALTIC STATE PROJECT WAS COMPLETED?

Med-Sense was put on the web by the Latvian Club on Consumer Protection. They have done small projects on



“The project had great impact on people now working on national drug policy”

the use of pharmaceuticals. Not especially on drugs, but more on consumer awareness.

I worked with the Latvian Drug Information Center for years and was editor of its independent drug bulletin, *CITO!* until 2001. Then the Drug Information Centre became affiliated with the national drug agency and there was a discussion about if we should have two drug bulletins or one. The decision was made to have one because the audience is very limited in our small country. I am very happy about this decision because now *CITO!* goes to all of the country's pharmacists and to many doctors, it's like the *Drug and Therapeutics Bulletin* in the UK.

However, the pharmaceutical industry was always very interested in the people who were working on these things and that's a pity. They took some good people.

WHAT IS THE SITUATION TODAY?

Drug promotion is still a problem, but doctors and health care professionals are more aware of drug promotion and see it as a problem and know that a lot can be done about it.

On rational drug use, all that we did from 1991 to 1994 on generics and also on educating health care professionals actually changed the curriculum taught at medical schools. Now students have to have a basic knowledge of INNs and generics. That wasn't there 15 years ago.

The next big issue for us is vaccines. Everyone is talking about pharmaceuticals, but vaccines are a growing problem. The approach is that vaccines are always good. But you have to wonder how useful and effective they really are. And how much public money should be spent on them. Doctors are getting promotion on new vaccines. It's a new field of work.

The people who started in HAI back in 1991 are now working within national institutions in this region. There is a need for networking and training for the next generation. We need a new generation of HAI.

What were also important were the personalities within HAI, the brilliant people, that was the biggest value. HAI was a university for me.

1994

- HAI criticises the 1994 revision of the IFPMA Code of Pharmaceutical Marketing Practices saying that its new wording still allows companies to evade the code by hiding behind weaker national legislation or rules and includes no meaningful sanctions for code violators.
- BUKO Pharma-Kampagne publishes its second study showing that almost half of the drugs German companies sell in Third World countries are irrational. With the help of HAI groups in Brazil, Chile, Mexico, Peru, The Philippines, Thailand and Switzerland, BUKO also evaluates the quality of drug information accompanying benzodiazepines sold by German and Swiss companies.
- HAI and Women's Health Action Foundation co-produce *Immunological contraceptives: designed for populations not people* to highlight concerns about 'anti-fertility vaccines', a new type of birth control under development.
- The independent drug bulletin *CITO!* is launched in Latvia to meet the information needs of medical professionals in the country. However, the Latvian government withdraws financial support for *CITO!* after a critical article on loperamide and problems related to the use of antidiarrhoeals lead to charges that the bulletin is trying to kill local industry because its producers are agents of Western pharmaceutical companies.
- The UK's National Consumer Council publishes *Secrecy and Medicines in Europe* examining the plans for the European Medicines Evaluation Agency (EMA) and calling for a much greater commitment to transparency and consumer representation.
- After ratifying the European Economic Area agreement, Norway is forced to remove its 'needs clause' when considering approval for pharmaceuticals.

1995

- E-drug starts disseminating messages on rational drug use, essential drugs and related pharmaceutical issues through an electronic list serv. French and Spanish language versions follow.
- The European Medicines Evaluation Agency (EMA) opens in London.
- HAI holds a series of workshops on women's health and pharmaceutical issues at the NGO Forum that precedes the Fourth World Conference on Women held in Beijing, China. A number of HAI contacts take part in various NGO workshops related to the UN meeting.
- HAI launches its poster "What do women look for when choosing a contraceptive?" which shows an international selection of advertisements for contraceptives (mostly aimed at doctors) which present false promises, empty slogans, sex stereotyping and the assumption that women can't think.
- Women's Health Action Foundation launches *A healthy balance: women and pharmaceuticals* at the NGO meeting preceding the Beijing women's conference.
- HAI Europe holds its annual meeting in Eastern Europe for the first time as almost 40 participants meet in Riga, Latvia to discuss rational drug use. During the event, participants from Estonia, Hungary, Latvia, Lithuania, Poland and Moldova tell participants about the pharmaceutical situation in their countries.
- HAI starts sending out *HAI Alert*, a quarterly packet of information on developments in the field of drug policy aimed at drug regulators in developing countries and in Eastern and Central Europe.
- HAI takes an active role in an international meeting of women's health groups opposing work on 'anti-fertility vaccines' held in Canada. As a result, Canada's development research agency (IDRC) agrees to stop funding clinical trials of 'anti-fertility vaccines'.
- Joel Lexchin writes *Deception by design: pharmaceutical promotion in the Third World*, exposing double standards in the pharmaceutical marketing and promotional practices in developing versus industrialised countries.
- HAI publishes *Problem Drugs* as a book (previously an information pack) with the publisher Zed Books in the UK.

Kirsten Myhr, pharmacist, HAI Association Board member

"HAI has opened my eyes"

"I 'met' HAI for the first time at a conference, I cannot remember which, where Wilbert [Bannenberg] had a poster illustrating the marketing of a bad drug. This was probably shortly before 1985 which is the year I went to Botswana. I do not think I was a member then, but I did bring some HAI material to Botswana, I think. During my three years in the country, the Drug and Therapeutics Committee had a request from a doctor for that medicine. I remember telling the committee that it would be over my dead body!

HAI has opened my eyes to the important role consumers can play, that you do not have to be a doctor or pharmacist to know about drugs. To meet people from such different backgrounds but with a common goal has been

fantastic. To go out together for a meal in Geneva, with friends from all corners of the world, share a meal, and laugh at the same things....

HAI also brought me in touch with E-drug which was started by Wilbert. In 1995 I had no email and my computer did not have enough capacity for email and E-drug. But Wilbert convinced me that I needed to read E-drug and so I upgraded to email, not Internet, and ended up sharing moderation of E-drug with him. I have met many new friends by doing that!

Over the years, I think HAI's role has changed from being a sort of activist network to a network which stands for 'evidence-based knowledge'. What has not changed is its role as a consumer advocate, independent from pharmaceu-

tical companies, governments and regulatory authorities. And yes, it still has a role! All the projects we currently work on will be important for the foreseeable future - unfortunately. The role will be to continue to protect and inform consumers by looking at the industry critically, ensuring affordable medicines, fighting direct-to-consumer advertising, supporting publicly funded research and development etc".



Mohga Kamal-Yanni,

Senior health & HIV policy advisor, Oxfam, Oxford, United Kingdom

"Enabling NGOs' collaboration"

"I think HAI has played a key role in enabling NGOs' collaboration on medicines, especially in relation to work with WHO. HAI also kept the topic on the political agenda for decades! The

price study is a major breakthrough on medicines. The work on intellectual property and global public-private partnerships has also been excellent".

1996

- In October, HAI Europe and BUKO Pharma-Kampagne organise a seminar on the GATT/World Trade Organization (WTO), Pharmaceutical Policies and Essential Drugs. The seminar originates from HAI members' concerns on repercussions of the GATT (General Agreement on Tariffs and Trade) and the newly created WTO on public health and access to pharmaceuticals, especially essential drugs. HAI Europe later releases the meeting report *Power, Patents and Pills: An examination of GATT/WTO and essential drugs policies* for broad distribution.
- In collaboration with a group of European NGOs, HAI Europe develops *A Guide to NGO Essential Drugs Policies* to help ensure that scarce resources are well spent and that the best possible use is made of money, medicines and human resources.
- HAI and the Dag Hammarskjöld Foundation bring together a group of drug experts to discuss the need for greater openness and accountability in drug regulation. The participants draw up a statement on transparency that sets out the problems caused by excessive secrecy and calls for greater access to drug information held by regulatory agencies. *The International Journal of Risk & Safety in Medicine* publishes the meeting's papers.
- WHO issues its *Guidelines for drug donations* reflecting the consensus reached by the major international organisations involved in humanitarian aid.
- HAI raises strong objections to an announced World Bank/IFPMA fellowship and asks the president of the World Bank to reconsider the appointment considering that the World Bank is the largest single financier of health programs in developing countries and the Newly Independent States and is committed to cost-effective pharmaceutical policies based on the WHO Essential Drugs Concept. Considerable opposition is also raised among some World Bank staff.

- HAI Asia-Pacific publishes a study finding enormous differences in retail drug prices after looking at 22 commonly used essential drugs in 29 countries.
- Six years after publishing its study promoting rational drug use for children with diarrhoea, WHO reports that, in total, 16 countries have reported 21 regulatory actions to rationalise this type of treatment.
- Finnish HAI contacts Meri Koivusalo and Eeva Ollila write *International organizations and health policies* which focuses on the institutions' policies in such controversial fields as primary health care strategies, health care reform, pharmaceutical policy and reproductive health.
- HAI publishes *An ill for every pill: recent examples of unethical and misleading marketing*.



1997

- Fifty African HAI contacts come together in Nairobi for the HAI Eastern Africa training workshop “Promoting rational drug use in the community”, laying the foundations for the official start of HAI Africa. Later the meeting report *Fragile economies, flooded markets* is released internationally.
- David Gilbert and Andy Chetley examine new trends in drug promotion to examine how pharmaceutical companies have found innovative ways to promote their products despite national and regional restrictions on direct advertising.
- After surveying 2,000 UK consumers, the National Consumer Council reports that a great deal of consumer information is poor quality or written in such a way that it is difficult for users to understand.
- In the 1997 World Health Report, WHO calls for the extension of the essential drugs policy to industrialised countries saying “essential drugs are not for poor countries only, or for rural areas only. The concept of essential drugs is just as valid in developed countries, in teaching hospitals, and in health insurance scheme”.
- HAI and ISDB send the EMEA suggestions to improve the agency’s policy on transparency as both believe a great deal of the information submitted to the agency is veiled in secrecy.
- The UK’s Medicines Control Agency starts encouraging hospital pharmacists to report adverse drug reactions in the hope of increasing the information it receives about such reactions.
- UK researchers John Abraham and Graham Lewis explore the effects that harmonisation of European drug licensing procedures has on the assessment of drug safety and the effectiveness of regulators.
- At a meeting of medicines agencies, the European Commission’s pharmaceutical unit, industry directorate (DG III) states that the EU plans to reconsider its earlier decision to ban direct-to-consumer advertising of prescription drugs.
- HAI Europe hosts a seminar on World Bank pharmaceutical policies and access to essential drugs in Oslo.

Memories on HAI from Barbara Mintzes

“The commitment and message haven’t changed”

BARBARA MINTZES WORKED FOR MORE THAN FIVE YEARS AS PUBLICATION MANAGER IN THE HAI EUROPE OFFICE IN AMSTERDAM. AFTER LEAVING THE STAFF IN 1996, SHE RETURNED TO CANADA AND EARNED A PHD IN EPIDEMIOLOGY. BARBARA REMAINS EXTREMELY ACTIVE IN THE HAI NETWORK, WORKING BOTH ON CANADIAN HEALTH ISSUES AS WELL AS HELPING TO LEAD HAI’S WORK ON DRUG PROMOTION.

HOW DID YOU BECOME ACTIVE IN HAI?

I joined the HAI network to begin with because of my work with DES Action Canada – working on one unsafe, unethically marketed pharmaceutical. I had started out working with a local women’s health organisation (not even a regional or national group) in the early 1980s. At the time there had been no work done to raise awareness of problems of DES exposure or help women who were exposed to obtain appropriate health care or support. Through that work I started to become aware more widely of pharmaceutical policy concerns and also began to work with the international DES Action network. This is where I met Ellen ‘t Hoen, who introduced me to HAI and the rest is history.

HAS HAI’S ROLE CHANGED SINCE ITS CREATION?

I wasn’t involved in 1981 but I think there are three main differences. One is the focus on broader policy issues and

upstream solutions rather than getting rid of individual problem drugs or problem promotional campaigns. The second is the realisation that both unethical marketing and inadequate access to needed drugs are problems of industrialised countries as well as developing countries, so there is a focus on Europe more strongly than in the past, as well as on the countries of the South. Thirdly, trade, patent policies and market issues have become much more important in HAI’s work. Maybe fourth is a realisation that some upstream changes are needed to really make a difference – for example research and drug development that is publicly inspired rather than market inspired to meet the most pressing unmet health needs globally. I don’t think this is a real difference, just a shift in the amount of focus.

In terms of HAI Europe’s work, the work on European issues was always recognised as needed but was less central to

HAI’s mandate. Now it is one central strand, and is recognised as important both for public health in Europe and for its effects on how European companies act globally. There are also some solutions that have been recognised for years in the South that have become more important in the North as public payers begin to find the costs of medicines unsustainable. Essential drugs policies have provided a model for payment policies used by some European national insurers.

Another difference is that many of the people who started HAI have stayed with HAI although they are now much older, and some of the wild-haired radicals of the past are now to be found wearing suits, looking very grey and respectable, and speaking with an enormous amount of authority. The wonderful side to this is that essentially the commitment and message haven’t changed. This is also not really new since as long as I’ve

known the organisation HAI has been a mish-mash of people from different walks of life and positions. That has also been a strength – has helped amplify HAI's work by taking it in different directions and to different audiences.

WHAT ARE SOME OF YOUR MOST VIVID MEMORIES FROM YOUR YEARS AT HAI?

Tents in the mud in China! I was responsible for coordination of a series of workshops that HAI organised at the 1995 NGO Forum on Women, held in Huairou, just outside of Beijing, just before the official UN meeting [4th International Conference on Women]. We had a very international series of workshops with speakers from all over the globe. I had found out where Lisa Hayes, then working for Women's Health Action Foundation, and I were going to stay, and let all the speakers know to come to the main entrance of our building at a certain time and date. When we arrived, I discovered that the address I had was for a whole kilometer of buildings. That was just the first logistical problem we encountered.

Second, the logistical nightmare of receiving boxes of *Problem Drugs* we had

shipped ahead of time, finding a place to store them near where the workshop would be held. Eventually I abandoned all protocol and stashed them in a corner of a computer centre where they blended enough into the chaotic scenery that no one noticed. Then there was the workshops themselves. They were mainly scheduled to be held in brightly colored, inflatable tents. We held the first workshop outside instead because the tent needed a pump running constantly to hold up its inflatable posts, and the noise made it hard to hold a workshop. Little did we know that this was the least of our problems. It then started to rain and the electric pumps stopped functioning, leading to islands of coloured cloth on a sea of mud. Negotiating last-minute, space-sharing in more permanent structures had to be the hardest part of the whole event, then letting both the presenters and the audience know where the workshop was being held. We managed to officially move one workshop to an indoor room. When halfway through the workshop the overhead projector stopped working, it was nothing compared to everything that had gone before.

Another memory involves the rational drug use project in Poland. I was responsible for HAI's part in the co-sponsorship of a project with the Polish Consumer Federation to promote rational drug use in Poland. The main focus of the project was a survey to assess consumer medicines information needs and production of information materials highlighting key issues that had been identified, including a Polish edition of *Med-Sense* – HAI's medicine information box. We were carrying out this project in 1995-1996, amid major economic and political shifts in Poland. The Consumer Federation knew that despite these shifts the medical system in Poland remained very traditional and conservative, and that the project would not succeed unless there was major buy-in from both the Ministry of Health and health professionals. They were aware of an undercurrent of distrust that also came from a difficult economic situation: why did a consumer group have funding to provide medicines information when there weren't enough information materials available for physicians? They thought it would be helpful to have a meeting together with some international HAI people. We

invited Ilze Aizsilniece from Latvia, a family physician who had started Latvia's independent drug bulletin, and Andrew Herxheimer from the UK. Ilze provided the practical on-the-ground experience with a similar project in Latvia as well as her own expertise, and – as an eminent clinical pharmacologist who strongly supported consumer drug information – Andrew would add just the extra measure of legitimacy to the project that we needed.

The meeting was held in winter, in the evening, in a very dark Ministry of Health building. We sat in a long thin room, with the Under-Secretary of Health for Pharmaceuticals and a prominent clinical pharmacologist on one side of the table, Monica, the key representative from the Consumer Federation for the project, a just-graduated clinical pharmacologist colleague who was also working on the project with her, Ilze and myself on the other side. Andrew's plane was late. One side of the table was mainly female and on the younger side. The other was male and greying. I'm sure you can guess which side was which.

There was a sparring tone to the questions, and they seemed to become more and more hostile as the evening progressed. We were standing our ground but it wasn't clear which way this meeting was going. The sticking point was the slogan on *Med-Sense*, "less is better". They said, "How can you say less is better? Don't people need to finish a course of antibiotics once they start?" We agreed but stuck to the importance of the principle, in terms of avoiding unnecessary and trivial medicine use. Finally Andrew showed up, oblivious to the increasingly hostile vibes. He added his two bits to the question of less is better – fairly similar in content to what we'd already said but with a "this is obvious" tone to it. The conversation turned to why consumers need medicines information and again Andrew contributed as though this was of course necessary and important. Not long after the Under-Secretary of Health pulled a list from his shirt pocket with concrete promises of support – a list he had clearly written before the meeting started. I always wondered what was in his other pocket.



“Many of the people who started HAI have stayed with HAI”

1998

- After more than 80 children died in Haiti in 1995 as a result of taking contaminated, mislabeled cough syrup, the WHO brings together national drug regulatory authorities, pharmacists, traders, chemical and pharmaceutical manufacturers, customs officials and NGOs, including HAI, to set out recommendations to avoid future tragedies.
- HAI Africa and HAI Europe co-sponsor a regional workshop on networking for rational drug use in southern Africa, bringing 34 participants together in Johannesburg and later publishing the meeting report *Moving in from the margin: Increasing consumer involvement in the formulation and implementation of national drug policies*.
- On behalf of HAI Europe, Barbara Mintzes writes *Blurring the boundaries: New trends in drug promotion* which explores the escalating amount of promotional activities undertaken by the pharmaceutical industry to sell products and the sophisticated new ways in which medicines are promoted to bypass current regulatory controls.
- HAI brings together members, patients groups, WHO and NGO representatives to weigh the risks and benefits of pharmaceutical industry sponsorship. The meeting's papers are later published in *The Ties that Bind: Weighing the risks and benefits of pharmaceutical industry sponsorship*.
- HAI coordinates the first WHO/Public Interest Roundtable on Pharmaceuticals between international health NGOs, WHO Director General Gro Harlem Brundtland and senior WHO staff members.

- The World Health Assembly ends without a consensus on a resolution text regarding the Revised Drug Strategy. A large part of the controversy arises when delegates from several developed countries object to wording that would place public health interests above commercial interests. HAI and other groups lobby for the original draft text approved by the Executive Board, saying that championing trade priorities above health would be odd in a forum specifically created to protect public health.
- BUKO Pharma-Kampagne publishes "Talking to industry: BUKO's experience" to share insights on how NGOs can start a dialogue with the pharmaceutical industry.
- For the first time, two HAI representatives attend the World Trade Organization's Ministerial meeting.
- A US study reveals that consumers have access to approximately 10,000 websites offering medical information. It estimates that almost two-thirds of the people who visit the web seek health and medical information.

Bas van der Heide, Senior Policy Officer, Nutrition,
Health Protection and Prevention Department, Netherlands Ministry of Health

“HAI has kept alive the Essential Drugs Concept”



“I think HAI’s most significant thing is the achievement of a global network of like-minded individuals and organisations that have worked towards a common goal without too much of an organisational structure. You realize that this is unique once you become part of a real organisation like a Ministry of Health (or the EU or the UN). I think HAI has kept alive the Essential Drugs Concept and put important issues like drug promotion and access to essential drugs on the global agenda and helped make solutions work. Whenever people ask me what I did for HAI, I think back

to all the work we did on lowering the price of ARVs [antiretrovirals] and the discussion we started on the World Trade Organization (WTO) and patent issues.

Although I was coordinator of HAI Europe for five years, I had joined HAI long before that because Wemos was a member of HAI. While I was at Wemos, I worked on topics ranging from advocacy on export legislation to drug promotion and drug donations. When I became HAI Europe coordinator, I faced the impossible task of replacing Catherine [Hodgkin] and Ellen [’t Hoen]. Now I’m working for the Dutch Ministry of Health. My experience at HAI influences my work there. I think it helps me understand the industry and consumer groups when they come and advocate for anything at the Ministry. There are many areas where food and medicines intersect (e.g. functional foods, food supplements, etc). There are similar policy discussions (e.g. the influence of marketing, self-regulation versus strict controls, transparency, dealing with side effects, etc.). Seen it, been there. However, not much has changed after all these years.

One of the most important developments affecting HAI is that information is available everywhere now through the Internet. HAI had an important role in disseminating information. I think that role is much more limited now. When HAI started, the primary health care concept was new and HAI’s focus on drugs was always within the context of that concept. It is not only doctors who tend to choose the easy solution (a pill for every ill): networks also go for the sexy issues where the funders are. After 25 years, HAI has moved away from these roots. I do not think this is a problem though. I think it is crucial to fund drug research in such a way that the poor people who need these drugs can afford them. This can help develop models for many things we need for the common good. I think HAI’s role is to further build and strengthen regional structures and to bring together people with innovative ideas. Health for all by the year”

1999

- Delegates to the World Health Assembly adopt a resolution aimed at improving access to essential medicines. It is the first time such a resolution substantially addresses trade-related issues and discusses the relationship between commercial interest and public health concerns.
- At the international HAI/MSF/Consumer Project on Technology seminar held in November, participants endorse a statement to WTO Member States on access to medicines, urging the creation of a WTO standing working group on access to medicines and pushing national governments to develop mechanisms to ensure funding for research and development for neglected diseases.
- The battle over the world’s most controversial sleeping pill, Halcion, is described by John Abraham and Julie Sheppard in their book *The Therapeutic Nightmare*.
- HAI discovers that an employee from pharmaceutical firm Merck, Sharp and Dohme has been seconded to the staff of WHO’s Tobacco-Free initiative and raises objections about the situation’s potential conflict of interest and the organisation’s lack of guidelines on industry collaboration.
- Calling the current ban on direct-to-consumer advertising “out of phase with world developments” the head of the European Commission’s pharmaceutical unit in the industry directorate recommends creating a task force to re-examine the region’s ban on DTC ads.
- *La revue Prescrire* turns down an invitation to become a WHO collaborating centre due to the bulletin’s growing concerns about WHO’s cooperation with the pharmaceutical industry.
- HAI is designated an ‘interested party’ by the EMEA granting it greater access to information from the agency and enabling it to participate in more of its work.
- BUKO Pharma-Kampagne examines the marketing of German pharmaceuticals in Third World countries in the publication *Poor choices for poor countries*.
- ISDB holds its first meeting for bulletins in Central and Eastern Europe and the Newly Independent States.

Memories on HAI's impact and importance by Alan Cassels

“An organisation that seemed to be doing what nobody else was doing”

ALAN CASSELS WAS INTRODUCED TO THE NETWORK THROUGH OTHER CANADIAN MEMBERS OF HAI, AND HAS BEEN RESEARCHING AND WRITING ON ESSENTIAL MEDICINES AND DRUG PROMOTION FOR NEARLY A DECADE. HIS OWN RESEARCH IN CANADA LARGELY FOCUSES ON CONSUMER DRUG INFORMATION ISSUES AND THE ROLE OF THE MEDIA IN OUR UNDERSTANDING OF MEDICAL ADVANCES. ALAN WORKS AS A DRUG POLICY RESEARCHER WITH THE UNIVERSITY OF VICTORIA, IN VICTORIA, CANADA AND HE'S A MEMBER OF RESULTS CANADA, A CITIZENS' ACTION GROUP COMMITTED TO CREATING POLITICAL WILL TO END HUNGER AND ABSOLUTE POVERTY. BELOW ARE SOME OF HIS THOUGHTS ON THE MILESTONES MADE BY HAI AND THE ONGOING IMPORTANCE OF CITIZENS' ACTION.

WHAT ARE SOME OF HAI'S MOST SIGNIFICANT ACHIEVEMENTS?

My short time associated with HAI (since 1999) gives me no credibility whatsoever to say what stands as this organisation's "most" significant accomplishment. But I would have to say from my perspective the "most" important event in the last seven years was HAI's co-hosting of the Access to Essential Medicines conference in November 1999 with MSF and the Consumer Project on Technology. These groups were able to raise the world profile of the access issue and draw media attention to one of the most overlooked aspects of international health.

Just days before the mighty siege in Seattle sparked by the World Trade Organization demonstrations we met in Amsterdam at an extraordinary conference that raised the level of moral outrage over seeing trade taking a huge and unwanted level of

precedence over public health. That outrage was enshrined on the streets of Seattle (what we called the "Battle in Seattle") and the world has never been the same since.

I remember a few things from the November 1999 Access to Essential Medicines Conference – the fiery rhetoric of fellow Canadian and [then] MSF President, Dr. James Orbinski who summed up the deaths of tens of millions of people around the world who lack the most basic medicines as inhumane and despicable. "Death by market failure" he called it. At that meeting I had the good fortune to meet other luminaries (in my mind, at least) people like Ellen 't Hoen, Jamie Love, Andrew Herxheimer, Charles Medawar, Bala, and David Henry, among others. I remember sitting on the boat during the canal cruise sandwiched between David Henry and Andrew Herxheimer and thinking, "Wow, these guys are as good

as it gets". Any organisation that attracts this kind of calibre of people – who mix high levels of both moral and intellectual virtue – are surely worth being associated with.

The next thing that I think is most important is the fact that the DTCA [direct-to-consumer advertising] virus has yet to spread worldwide to create a global pandemic of disease-mongering. This is due, largely, to HAI. With HAI's worldwide organisation, inspired networking, and thoughtful and targeted action our committed citizen activists shaped a situation where the EU had no choice but to eventually do what was right and rational – reject direct-to-consumer advertising of prescription drugs. This decision has had worldwide impact, going far beyond Brussels to nearly every corner of the globe. It has been a vital lever here in Canada where the commercial forces of drug marketers and media conglomerates are

salivating over a half-billion dollar drug advertising market, and continuing to pressure our health regulators that we just need to become more "like America". HAI has kept European citizens, and by proxy we Canadians, free from marinating in billions of dollars of drug advertising, selling us sickness while they push the patented cures. Thanks HAI.

WHY DID YOU JOIN THE HAI NETWORK? WHAT DOES IT ADD TO YOUR WORK?

I knew I found the right organisation when I learned in about 1998 (from colleagues Joel Lexchin and Barbara Mintzes) that there was an international organisation that seemed to be doing what nobody else was doing: making medicines issues political. That is to say, an organisation that made the pursuit of rational, people-centred prescription drug use a political priority, and used the tools of power and politics, advancing a cause on behalf of the world's citizens, especially those who have little voice in world affairs. But what drew me into the HAI network was largely because of HAI's middle name: Action. Here is an organisation that recognises how much of medicine use is inhumanely and grotesquely driven by commerce, exploited by the

rich and powerful at the expense of the weak and the ignorant. When I asked who was out there working, organising and doing actions that made a difference in the health of the poorest people on the planet a few important world organisations made the short list. HAI, in my estimation, is one of them.

Name any of the world's most pressing problems – the environment, climate change, corporate profiteering, dire poverty and inequity – and you see much of the same thinking happening: most of us recognise the world's problems, few of us actually do anything about them. To best capture how the HAI network enshrines action into its name I'd have to quote the quintessential consumer advocate Ralph Nader who said:

"The problem is that for every thousand exhortationists there's only about ten organizers. And that's not going to do it. There's just too many people exhorting and throwing the caveats all over the place and not enough rolling up their sleeves and organizing, or training organizers. That's what does it."

In my estimation, HAI "does it".



“What drew me into the HAI network was its middle name: Action”

2000

- As part of its European-level campaign, a coalition of NGOs, including HAI, organise the meeting “Advocating healthier trade – The World Trade Organization (WTO): Implications of EU Global Trade Policy on Health”.
- HAI Europe takes part in two consultations with civil society groups to discuss health and trade issues organised by the EU Commission on Trade.
- The People’s Health Assembly meets near Dhaka, Bangladesh to form a health agenda and set priorities.
- Directly after the World Health Assembly in May, a group of researchers and NGOs working on trade and access issues meets in Oslo to discuss access to essential drugs, including treatment for HIV/AIDS. The participants’ conclusions are summarised in a statement that emphasises consumers’ right to treatment and sets out obstacles in the way. They call on European governments to support developing countries in ensuring access to basic medical technologies and essential drugs while safeguarding the provisions found in international trade agreements such as TRIPS. The group, including HAI members, also calls on WHO to fulfill its role in monitoring and circulating information that will assist poor countries in procuring affordable drugs.
- HAI sends a critical response to WHO regarding its draft “Guidelines on Interactions with Commercial Enterprises”.
- In October, the HAI regional coordinators from Africa, Asia, Latin America and Europe meet in Amsterdam for the first international coordinators meeting.

- Wemos organises an international meeting on inappropriate drug donations.
- HAI Europe collaborates with BUKO Pharma-Kampagne to organise the seminar “Public-private ‘partnerships’: Addressing public health needs or corporate agendas?”
- The European Union creates a new directorate-general for health and consumer protection (DG Sanco).
- Swedish HAI member KILEN hosts an international conference on ways to increase consumer involvement in adverse effect reporting. Representatives from 60 countries are involved in the discussions which conclude with a consensus document setting out problems to be tackled.

2001

- HAI Europe warns against the possible negative impact of direct-to-consumer (DTCA) advertising in the European Union and other regions of the world. Charles Medawar and Barbara Mintzes write briefing papers on key issues involving DTCA and public health and the European working group on DTCA is established. HAI Europe works with interested members to build capacity on the subject in the network, devises an information kit, and sends out mailings on relevant issues involved in the advertising debate to key members of the EU Parliament and other interested parties
- Many HAI Europe contacts start national campaigns exposing the risks of DTCA.
- HAI Europe and Medico International co-organise the seminar “Sustaining access to medicines in Europe: The coming crisis” to emphasise that the problem of access to essential medicines is a European issue as well as one facing developing countries.
- HAI Europe and HAI Africa formulate an international response to WHO’s consultation paper aimed at updating the model essential drugs list procedures.
- *HAI Lights* underscores the risks involved in public-private interactions when it publishes Anita Hardon’s examination of the GAVI initiative entitled “Immunisation for all? A critical look at the first GAVI partners meeting”.
- HAI Europe sets up a regional working group on public-private interactions.

- AIS organises the first Latin American conference on access to essential drugs in partnership with MSF and Agua Buena, a Costa Rican NGO.
- *Holding corporations accountable: corporate conduct, international codes and citizen action* written by Judith Richter is published.
- A group of 80 countries led by the African bloc and supported by public health advocates claim victory in gaining commitments from wealthy nations on ensuring public health protection above patent rights at the WTO meeting in Doha. The meeting’s declaration on TRIPS and public health clearly recognises the potentially dangerous side effects of the TRIPS agreement and gives teeth to measures that countries can use to override them.
- WHO/HAI medicine prices project starts with a first meeting of the project’s advisory and steering groups in Amsterdam. The methodology is developed throughout the year and pilot tested in four countries.
- The European Commission creates the G10 which includes discussions on DTCA. HAI Europe lobbies G10 members to reject the proposal to allow DTCA in the EU.

An Interview with Marg Ewen

“We are recognized as experts”

AFTER EIGHT YEARS AS A SENIOR ADVISOR WITH THE NEW ZEALAND MINISTRY OF HEALTH, AND INVOLVEMENT IN THE INTERNATIONAL SOCIETY OF DRUG BULLETINS, MARGARET EWEN JOINED HAI EUROPE'S STAFF AS PROJECT MANAGER IN 2000. IN ADDITION TO WORKING ON MEDICINE PRICES AND DRUG PROMOTION, MARG WAS COORDINATOR OF THE REGIONAL OFFICE FROM 2001-2005. TODAY, MARG REMAINS ON HAI EUROPE'S STAFF AND DEVOTES HER TIME TO DIRECTING HAI EUROPE'S INVOLVEMENT IN THE MEDICINE PRICING AND DRUG PROMOTION PROJECTS, BOTH BEING CARRIED OUT IN COLLABORATION WITH WHO.

WHY HAS HAI EUROPE CHANGED ITS MANNER OF WORKING, NOW TAKING ON PROJECTS LIKE MEDICINE PRICES?

Those that have the difficult task of raising funds know that donors have changed. Rarely is core money given now – it's project or thematic funding. However, we haven't moved to projects for the money – however much it is needed. We have done it because the issues were crucial and weren't being addressed. The difficulty comes when the evidence is lacking. Before the pricing project started, how much did we really know about the prices of medicines, about availability, about mark-ups, about taxes? Was it enough to campaign nationally for policy changes? The members of the WHO/NGO Roundtable on Pharmaceuticals didn't think so, hence their decision to undertake this project. We knew there was a problem – HAI's work in Asia had shown that. But policy has to be based on the complete

picture and parts were missing. The evidence itself has to withstand attack so for the pricing project that meant first developing a methodology so that comprehensive, reliable data could be gathered. We clearly had a project on our hands – but one where advocacy was going to be essential.

In the beginning it was quite tough – not only doing the hard slog of developing the methodology but having people in the network asking why I was spending so much time on this project. I made a conscious decision that price issues were right – both for HAI and for me – and that people had to understand that results would take time. I have to admit though that some days I, too, am impatient. There has been so much interest in undertaking surveys – more than I dared hope for. About 50 surveys are now completed or nearing completion, and every week or so I receive an email from a country or initiative interested

in undertaking a survey. This is just what we want – but it also presents a challenge. We have had to spend a lot of time holding workshops, supporting surveys, checking data and their interpretation. But of course it has had its reward too. There is now a very large and growing family of people who know how to collect and analyse price data, and who are concerned about price and availability issues. And it's not just NGOs – many surveys have been undertaken by Ministries of Health and academia or collaborations of these groups.

WHAT WOULD HAVE HAPPENED IF HAI DIDN'T START DOING PROJECT WORK?

To be honest, when I started working at HAI Europe I felt we were more a follower in the access campaign, not a leader. Sure, HAI was consulted and our name appeared on documents but I didn't feel it was giving us great recognition at that time. Now in HAI Europe's three projects – pricing, promotion,

and public-private interactions – we are recognised as experts and leaders in these fields. That has to be good for HAI.

WHAT DO YOU SAY TO THOSE WHO BELIEVE HAI'S GONE SOFT ON WHO?

I say give me an example where we didn't speak out on an issue that HAI Europe was working on because of our collaboration with WHO. When WHO published their report on priority medicines, we spoke out against aspects of it. Undertaking projects with WHO didn't stop us from doing that.

I think it's short-sighted not to collaborate with WHO on an issue like medicine prices. We both want the same outcome – more affordable medicines. Because WHO realizes our abilities, they help us to work closely with governments. You have to remember, in some of these countries we don't have any members. So we need this support to get a place at the table.

When I feel it's warranted, I will stand my ground with WHO. Just ask Richard Laing. The names and logos issue is infamous. WHO's Director General Gro Brundtland would not allow either one on the cover of the manual. I was

prepared to walk away from the collaboration rather than give in to her. We at least got the names on. When our EU funding proposal was rejected, WHO suggested that we use our remaining money revising the manual and holding a conference. I disagreed. I wanted advocacy and policy changes. And that is what we are now doing.

There are a lot of people in WHO who really support this project. We need each other, and I feel this collaboration works.

WHAT ABOUT HAI'S RELATIONSHIP WITH GOVERNMENTS INVOLVED IN PRICING WORK?

The Ministries see us as experts in this field who can help them. I think our approach of providing expertise and working collaboratively is right and I hope it will take us far on this issue. Criticizing without providing solutions won't get the results we need.

We want pricing policies implemented so that people, especially the poor, have access to affordable medicines. We have the evidence, now it's time for advocacy. That's what we'll be doing in the next three years.



“Criticizing without providing solutions won't get the results we need”

Carolyn Green, Senior Technical Advisor, Care & Support,
International HIV/AIDS Alliance, Brighton, United Kingdom

“The world has changed”

“I joined HAI around 1986 when I started working for the UK non-profit supply organisation ECHO International Health Services. My work brought me into contact with health work in over 40 countries and there were some clear gaps between what was going on and what I already knew about rational drug use, value for money and public health. Joining HAI was a way for me to get closer to the discussions and developments that were going on, and still go on, on those issues. My work has re-focused onto community responses to HIV for the last ten years, and now that ARV treatment is being scaled up the same issues are coming to the fore. For some years, the essential drugs world was running parallel to the HIV world and there was not enough dialogue or sharing of experiences around health rights and essential medicines. Now I believe we have moved on from that and insights from HAI can still inform my work.

HAI Europe seems to have focused more on issues within Europe in the last few years, and seems to have lost some relevance to international work in resource-poor countries. It is not clear to me how much HAI is doing to influence EU policies that affect people in those countries e.g. on funding, trade, patents and univer-

sal access to treatment, care and prevention of disease – this latter may be seen primarily as an ‘AIDS’ agenda, but in reality it should be a universal health agenda. Just as countries are being pushed to set national targets on access to treatment for HIV, so they ought to be pushed to set other targets and create enabling legal, economic and social environments for them to be reached. Health is said to be moving up the lists of national priorities in many countries because governments are seeing the dire effects of neglecting it for so long – not only in terms of disease burden, but (probably more) in terms of national productivity and security.

Could HAI perhaps refocus its energies to work more on these key policy issues, as well as (or maybe instead of) on the laudable but more practical issues of (for instance) drug pricing? There are also specific medicine-related issues that need far more attention than they are getting, for instance treatment for children (only 5% of people on ARV treatment are children when it should be 15%), access to the right narcotics for substitution therapy for drug users, and the same for treatment of moderate to severe pain – too many countries have such tight narcotics regulations that

hardly anybody has access to them for legitimate medical uses, and too many prescribers do not understand how to use them effectively and safely.

I believe HAI has been instrumental in building a strong and lasting international network of dedicated professional health activists, especially around the issues of health rights and the key role of access to safe, affordable, effective medicines. It has also developed strong relationships with other bodies active in this area, notably WHO Medicines, the Ecumenical Pharmaceutical Network, MSF and the E-drug network. This has enabled many HAI members, working in many countries, to stay in touch, share information and take the whole essential drugs and health rights agenda forward over the last 25 years. I’d say to HAI: keep going, keep the issues in the public eye, but also take a cool look at how the world has changed in those 25 years – particularly in a world which did not know HIV in 1981 and now has over six million people needing treatment, with the majority still unable to access it. HIV is no longer something for ‘others’ to look after, it’s everyone’s problem, but we also have to look at how we can protect people’s health rights across the board, not just around HIV”.

2002

- **As the European Parliament starts to consider allowing direct-to-consumer advertising for some drugs, HAI Europe and the European Public Health Alliance co-organise a symposium examining the role of DTCA in providing prescription medicine information to consumers.**
- **The HAI Europe office produces its first handbook for members.**
- **The WHO Essential Drugs List celebrates its 25th anniversary.**
- **Physicians for Social Responsibility in Finland carries out research on almost 1,000 medical students’ attitudes towards the pharmaceutical industry, finding that almost half attend promotional events at least twice a month and that industry is seen as one of the most important sources of information for this group.**
- **GlaxoSmithKline, manufacturer of the world’s bestselling antidepressant, is found in violation of the pharmaceutical industry’s own code of marketing practices for misleading promotion about the drug paroxetine (Seroxat) in the UK. The case follows a complaint lodged by Social Audit.**
- **HAI Europe strongly criticises the Dutch Inspector General’s proposal to close down the government department that monitors illegal and unethical marketing practices within the drug industry, saying the need for such a department is growing, not shrinking.**
- **In October, the European Parliament overwhelmingly rejects the proposal to weaken the EU’s ban on advertising prescription-only medicines to the public. HAI Europe then lobbies the EU Health Council to also reject the proposal.**
- **Teaching-aids At Low Cost (TALC) includes HAI Europe’s Essential Drugs Policies Guide on its CD-Rom that is distributed to thousands of health workers in developing countries.**
- **HAI Europe, MSF and Oxfam agree to have a jointly funded person in the HAI Europe office acting as a central resource for the global access campaign. The agreement goes on for two years.**



Some recollections from Lisa Hayes

“The dedication of its staff and members”

LISA HAYES JOINED THE HAI EUROPE STAFF IN 1996 AFTER WORKING AT A NUMBER OF ORGANISATIONS IN THE NETHERLANDS THAT WERE MEMBERS OF HAI INCLUDING IOCU AND THE WOMEN'S HEALTH ACTION FOUNDATION. SHE DIRECTED HAI'S PUBLICATIONS AND COMMUNICATIONS WORK FOR SIX YEARS BEFORE GOING TO WORK FOR MÉDECINS SANS FRONTIÈRES. NOW A FREE-LANCE WRITER AND EDITOR, LISA REMAINS A MEMBER OF HAI EUROPE.

The thing that continually strikes me about HAI is the dedication of its staff and members. Having been both a member and a staff member, I've seen the organisation operate through good times and bad. People get frustrated and even angry, there are disagreements on strategy or priorities, the funding is uncertain, but they don't give up – and they don't walk away. Not the true believers anyway! And there are plenty of those.

I joined HAI shortly after moving to Amsterdam from New York in 1991. My introduction to the network took place at the annual meeting in Woudschoten where I was representing IOCU. I came to the meeting without having been briefed by my boss on the recent breakup between IOCU and HAI Europe. (Somehow she thought it would be better for me if I didn't know anything about it.) After learning the history very quickly that weekend, I was surprised that no one

was unfriendly to me because of it. In fact, people, especially the office staff, seemed to be working hard to make me comfortable and improve relations with IOCU again.

During my time at IOCU and later at the Women's Health Action Foundation, Catherine, Ellen and Barbara (not to mention Rose and Babet) were a constant support, and a source of inspiration, laughter and friendship. By watching them in action over the years, they taught me a good deal. Catherine showed me how you can speak softly but still make your point and get people to agree with you. Ellen demonstrated amply that you can lobby anyone anywhere, preferably where there's free food and wine available (a talent I've never seen matched)! Barbara commiserated with me on the Dutch housing market and showed me how to edit with style, patience and humor.

When I joined the staff in 1996 because Barbara was

leaving, I began working with Bas van der Heide, the new coordinator who was fresh from Wemos. We both knew we had big shoes to fill. We worked hard, made some mistakes of course, tried to find the humor in things, and slowly started to feel that we were moving the network forward. Bas played a huge role in getting the Access Campaign going in Europe and together we wrote a lot of funding proposals and donor reports. Later, Marg Ewen joined the staff and the team got stronger and I gained a true friend. There were a lot of bumps along the way and way too much overtime worked getting reports done, emails sent out and preparing for meetings. I was exhilarated or exhausted most of the time. Yet I felt such a dedication to the people and the cause that I found it impossible to leave the organisation easily.

I've seen people make huge sacrifices to get things done for HAI. Members working for

free to write articles, reports, and even translate books. Staff giving up vacation days and weekends and putting up with criticism when it's long past quitting time.

When I left the organisation, I saw that HAI Europe was working to become more professional and treat its staff more humanely. Led by Anita Hardon, pensions were introduced, efforts were made to reimburse overtime hours, salaries were even improved. The whole way HAI worked

“I've seen people make huge sacrifices to get things done for HAI”

was changing. I was glad to see it happen as the network can't survive without a strong and dedicated core staff to keep all the balls in the air.

It has been a privilege to work for the network and to meet the people who believe in it and keep it alive. They are a formidable group. The discussions and debates I've taken part in have opened my eyes to the health situation in regions of the world I never knew about back in New York. And they've helped me see

how health problems and countries are more interconnected than most people think.

I'm an editor and writer by profession, not a campaigner. You won't see me standing up at a big international meeting to make a commotion (which I've seen a few HAI members and staff do quite effectively.) Yet by being involved in HAI's communication work for years, some of that activism has certainly rubbed off on me. I hope it rubs off on many more people in the years to come.

Jenny Hirst,

Co-chairman, Insulin Dependent Diabetes Trust, Northampton, United Kingdom

“Knowing that HAI is prepared to stand up”

“As a new member of HAI, I welcome the support and information we receive. We are one of the few patient organisations whose policy is not to accept pharmaceutical industry funding because of our belief that we should be uninfluenced, and be seen to be uninfluenced, by funding sources, and it can be a lonely position. Knowing that HAI is prepared to stand up for the needs of patients to have independent, evidence-based information and resists the growing tide of influence by the pharmaceutical industry offers us reassurance and encouragement.

We have been fighting an uphill battle against such influence and I believe that we have a wealth of experience to offer HAI. We know first hand the difficulties that patients face as a result of the heavy marketing to medical and health-care professionals of insulins, especially those that are the most expensive with little evidence of benefit and unknown long-term safety.

I congratulate HAI on its 25th Anniversary, and for the best interests of patients, hope that its collaboration with like-minded people and organisations continues for many years to come”.

2003

- Following an international campaign and advocacy effort spearheaded by HAI Europe, the European Commission votes in April to maintain a ban on the advertising of prescription-only drugs directly to the public. HAI continues the battle to ensure that the information consumers receive is not advertising in disguise and calls for consumers to have access to information that is truly objective.
- HAI and the WHO launch the manual *Medicine Prices: A new approach to measurement* at the World Health Assembly. The first regional pre-survey workshop is held in Cairo to assist investigators in using this survey tool. Price data collected using the methodology are lodged on HAI's website: www.haiweb.org/medicineprices.
- HAI starts a three-year global project on enhancing equitable access to AIDS medicines involving an examination of the benefits and risks in public-private interactions.
- Shortly before countries meet in Cancun for trade discussions, they adopt the "August 30th Agreement" which sets out steps to be taken in order for member countries to export medicines using compulsory licenses to member countries with insufficient manufacturing capacity.
- BBC-TV current affairs programme, *Panorama*, broadcasts the first of three highly influential programmes on safety problems with SSRI antidepressants, and the chronic failure of drug regulatory bodies in addressing them. Andrew Herxheimer, Charles Medawar and other HAI members play major parts both on camera and behind the scenes.

- Andrew Herxheimer and Charles Medawar subsequently produce two papers on consumer and professional reporting of adverse drug reactions (ADRs), an important step in helping to establish consumer ADR reporting as an essential pharmacovigilance tool.
- A group of public health advocates organise the Eurasia Drug Information Network in the Newly Independent States (NIS) region, comprised of drug information centres, Ministries of Health, medical professionals, NGOs, medical and pharmacy students, consumer groups and medical journalists in Kazakhstan, Moldova, Uzbekistan, Kyrgyzstan and Tajikistan.
- Farmaceuticos Mundi concludes a four-year project involving AIS in Nicaragua to promote access to drugs using community pharmacies.
- Medico International supports rational drug use for more than 150,000 Sahraui refugees living in camp cities in Algeria by developing a comprehensive system for distribution of essential medicines and treatment guidelines determined with community involvement.
- The DIPEX database highlights patient experiences with 10 diseases or conditions on its website.

Alison Linnecar,

Geneva Infant Feeding Association (GIFA), Geneva, Switzerland

“Maintaining the pressure on WHO”

“I would like to send my warm greetings and heartfelt congratulations to all of our friends at HAI. It takes courage and determination to fight these battles and to struggle on in the face of opposition from huge, commercial vested interests.

HAI and IBFAN reinforce each other in our advocacy and campaigning work, for example, in our work together on the WHO guidelines on interaction with the commercial sector, and before that on the campaign to alert women to the risks of taking the lactation-suppressant drug bromocriptine (Parlodel).

Both of our organisations are international networks, deriving our strength from the commitment and dedication of people, and from our strong grassroots base in communi-

ties and associations. It has been difficult at times to explain how we function as networks, and there has been pressure to adopt a top-down and more rigid hierarchy instead of a bottom-up structure that grows organically. So we provide examples of how our two networks can combine forces to work in international solidarity and reaffirm each other's work.

One of the most important things HAI has done is to maintain the pressure on WHO to counteract the influence of the medicines (drug) industry and the producer countries and to act as a countervailing force at all times to uphold the highest standards of consumer protection. We know how difficult this precarious balancing act can be – and how powerful are the opposing forces”.

Joel Lexchin, M.D., member from Canada

“Providing space for people passionate about social justice”

“HAI has done many worthwhile things in the past 25 years including promoting the rational use of drugs, the ongoing pricing project that Marg Ewen has spearheaded and lobbying at the various World Health Assemblies. Each of these, and many

more, are things to be proud of and indicate how a network with limited financial resources can overcome this limitation through the dedicated work of the people within the network. Indeed, it is providing the space for people who are passionate about

social justice as expressed in pharmaceutical issues that I consider to be the most significant accomplishment of HAI. The HAI network has nurtured many people and helped them develop their skills in being able to pursue their desire to make a change

in the pharmaceutical area. Some people have remained in the HAI network and some people have moved on to other areas but both groups are much the better for having been involved.

I joined the HAI network back in the mid-1980s for a number of reasons but primarily because the work that it was, and still is doing, was strongly in-line with my own interests and it also gave me a community of like-minded people to relate to. HAI has always provided a reference point for me to engage in discussions, collaborate in projects and to refine my thinking. The international aspect of the network means that I (and others in the network) get a wide variety of perspectives on our work that could not be achieved in any other way. These perspectives can be critical at times but at the same time they are always supportive. I am not talking to people who are questioning the fundamental values of what I'm doing, although they may be questioning how I am doing it. I also like the trips to Europe to see old friends and make new ones!

HAI's basic role hasn't changed since its creation in 1981 and it still has a crucial role to play now and in the

future. This is a case of “Plus ça change, plus c'est la même chose” [The more things change, the more they remain the same]. HAI's sophistication and range of activities has grown, the network has expanded dramatically but the ideals that were laid down at its beginning have remained the same. We started as activists trying to bring about significant reforms in drug use and we are still activists. However, we also are comfortable lobbying in Brussels, writing cogent analyses of issues, issuing press releases about our activities and engaging with top officials from the WHO and the European Union.

HAI's role has never been as important as it is now. There is a lot more general interest in pharmaceutical issues but at the same time, the influence of the pharmaceutical industry has grown as regulatory agencies depend on fees from the industry to operate, governments look at the industry more in terms of its economic benefits to their economies than in terms of the health benefits that come from rational drug use, and the research agendas and those doing the research are more and more dependent on money from the drug companies. HAI needs to be the

voice challenging the industry perspective and pushing forward the views of consumers and others who come at these issues from a social justice point of view”.



“HAI's role has never been as important as it is now”

2004

- Charles Medawar of Social Audit and Anita Hardon, scientific director of the Amsterdam School for Social Science Research co-author the book *Medicines out of control? Antidepressants and the conspiracy of goodwill* which focuses on issues surrounding increased antidepressant use in Europe and a UK government inquiry into the “looming antidepressant drug crisis”.
- Partly in response to the publication of *Medicines out of control?*, the UK Parliamentary Health Committee launches a major enquiry into “The Influence of the Pharmaceutical Industry”. Andrew Herxheimer gives evidence and Joe Collier, Charles Medawar and John Abraham act as special advisors to the committee, which publishes a highly critical report the following year.
- BUKO Pharma-Kampagne publishes *Data and facts 2004: German drugs in the Third World*. This fourth assessment of German pharmaceuticals exported to developing countries finds that once again many of the drugs are irrational or marketed without medical justification. Many of the preparations are found to be dangerous and quite a few are banned in Germany.
- After discussions with the Dutch government which holds the EU Presidency, HAI Europe decides to launch the Essential Innovation Project, to assemble a consumer perspective on mechanisms for spurring innovation and to further public needs-driven innovation in Europe.
- HAI contacts at the University of Cork investigate the role of patient groups in sustaining a healthy skepticism towards drugs.
- The Association DRUGS and KILEN co-organise a conference on safety in medicines for people in NIS countries aimed at improving pharmacovigilance systems in those countries.

- HAI Africa, in cooperation with the WHO, the Ministries of Health in Ghana, Uganda and Kenya and numerous partners carries out country-wide surveys on medicine prices.
- HAI Europe members participate in the G10 meeting convened by EU Trade Commissioner Liikanen. The theme is “A stronger European based pharmaceutical industry for the benefit of the patient”. HAI represents the view that the increase in incentives to industry is not necessarily consistent with public health needs and consumer safety and calls for restraint and care in the development of policy to avoid confusing the two.
- AIS brings together medicines specialists from 10 countries as well as the WHO and the World Bank to discuss free trade and access to essential medicines. A declaration is published and a video is made with key ideas brought out at the seminar. In Peru, AIS also participates in a national debate regarding the probable effects of the free trade agreement signed by Peru, Ecuador and Colombia on access to essential drugs.
- AIS provides comments to Peru’s proposal for a national drug policy. A policy is approved in December.
- The HAI/WHO project on drug promotion publishes reviews of database material that are included in *What we know, what we need to learn: Reviews of material in the WHO/HAI database on drug promotion*.
- AIS organises a workshop on generic drugs and bioequivalence involving drug experts from the region, including representatives of national drug authorities.
- The HAI/WHO project on medicine prices holds pre-survey workshops in Anglophone and Francophone Africa, Asia-Pacific, India and Central Asia.

Interview with Eduard Soler Cuyàs

“The problems we face are global, not local”

EDUARD SOLER IS A PHARMACIST WORKING WITH FARMACÉUTICOS MUNDI, AN NGO BASED IN BARCELONA, SPAIN THAT SUPPORTS LOCAL GROUPS RUNNING HEALTH PROJECTS IN DEVELOPING COUNTRIES. EDUARD DISCOVERED HAI AFTER A LONG SEARCH TO FIND LIKE-MINDED INDIVIDUALS IN EUROPE. IN 2005, HE BECAME ONE OF THE NEWEST MEMBERS OF THE HAI EUROPE ASSOCIATION BOARD.

HOW DID YOU FIRST GET INVOLVED WITH HAI?

I don't remember the first time I heard about HAI, because I had been working with AIS in Nicaragua for a long time. I found AIS Nicaragua long before I found HAI Europe. I was talking about international networking with Benito Marchand, who is a Belgian pharmacist working with AIS in Nicaragua. That's how I found out about HAI. That was about seven or eight years ago.

I found HAI by myself. I was trying to do some research on people working on the rational use of medicines. There are not a lot of people working on that in Spain and I finally found HAI. When I found HAI Europe and discovered they had an office in Amsterdam, I went there when I had a meeting there for another group. I wanted to go there to ask “What is HAI?” and to see the face of HAI. Until then, I only had ideas about it from the Internet.

I was very surprised when I got to the office. The image I had of HAI, the people who talked on behalf of HAI, was very different from what you see at the office. When you arrive there, you see there are only four people doing all of this work!

In Spain, people are not very involved in international networks. There are some groups working on malaria, but that's more linked to universities. That's not the kind of network that promotes research and lobbying. Plus the consumer associations in Spain aren't very strong. That's what also makes HAI so interesting. It's both the lack of people working on rational drug issues and the fact that consumer groups are more active on other issues.

WHAT DOES HAI GIVE TO YOU?

HAI helps me by getting me in touch with all of these people working on drug issues. It's nice to find other kinds of

organisations working in the same field, groups like BUKO, and meeting people and hearing about their work.

I use HAI to get more information about topics, to become more aware of different things moving in the world of promotion or other areas that otherwise I wouldn't know about.

The problem is I have a lot of work here in my own organisation, everyone has that, and I feel like I could get even more out of HAI, but I don't have the time. Sometimes I don't think I use it enough or as well as I should. For example, there are not a lot of Spanish groups working on drug promotion. One day I want to become more active on drug promotion, but I always have other things to do.

I joined the board last year. It was a nice surprise for me and I find it very important to do. I'm on the boards of two or three other national NGO



“I want to know how HAI can become more visible”

networks. I believe a lot in networks. You want to get involved, you want to learn about things, it's very important. Networks are important because the problems we face are global, not local. Sometimes there are good reasons to work locally but the big solutions need to be found on the global level. My organisation doesn't have an international network so that's another reason why I want to get involved in the international HAI network. I'm an individual member of HAI. My organisation is not yet ready to join. It is collaborating with the industry on some projects, but mainly buying essential drugs at cost-price for international humanitarian cooperation projects. I'm working from the inside on the changes we should make.

WHY IS HAI'S WORK CRUCIAL?

The work of HAI Europe is very important as it is the only network doing this kind of lobbying work in the European Union. This is crucial to do. At country level there is also a lot to do, but it's difficult to know exactly what to do. I know many members

are active at that level. It's easier to understand and get a sense of the discussion at the European level and to see the importance of lobbying there. Working on drug promotion and drug regulation at the European level is more important to me than doing it on the country level.

AND LOOKING AHEAD?

I want to know how HAI can become more visible in places like Spain. HAI has only a few contacts in Spain. How can we make it more known here? What support can HAI give to people who want to make it more visible? How can HAI get more people involved? I had to find HAI all by myself. How can we make it easier for others? There must be some kind of mechanism to do that. A year ago, we made a network of people interested in improving access to medicines in Spain. People from the universities, agencies, and NGOs and it's very difficult. There are only two or three active members. It would be nice to think about how HAI could help us manage and move it further.

2005

- The WHO/HAI project on drug promotion conducts a survey to ascertain what is being taught to medical and pharmacy students about drug promotion. Barbara Mintzes sets out the study's findings in the report: "Educational initiatives for medical and pharmacy students about drug promotion: an international cross-sectional survey".
- After lobbying by HAI Africa and others, a 10% tax on prepackaged, imported medicines is abolished in Kenya, Tanzania and Uganda.
- Following the global withdrawal of the arthritis drug rofecoxib (Vioxx) in late 2004, there is strong international attention both on the need to improve drug safety surveillance and the risks of direct-to-consumer advertising.
- HAI Europe organises a seminar on patients' reporting of adverse drug reactions to push the European Union to promote direct reporting by medicine users.
- Using survey data collected using the project's price measurement methodology, the WHO/HAI project on medicine prices undertakes an international comparison of chronic disease medicines. The findings are published in a report.
- HAI co-sponsors, with Social Audit, an international seminar held in London, to review and celebrate the many outstanding contributions made by Dr. Andrew Herxheimer, on the occasion of his 80th birthday. More than 80 people attend, many leading figures on rational drug use and consumer health and development issues.

Anita Kotwani, Department of Pharmacology, University of Delhi, India

"Increasing availability and affordability of essential drugs"

"I have recently joined the HAI network, in 2005. I completed a project on medicine prices with HAI in 2003 and was impressed by the dedication and professionalism of the staff. I am a technical coordinator for six medicine price surveys conducted in India.

essential medicines in developing countries. WHO and HAI are now focusing on the availability of essential medicines for chronic diseases. This can be accomplished by collecting real data in the field and then by advocating and lobbying for policy changes in the community".

I think HAI has a crucial role to play now – to increase the availability and affordability of

From the screenplay of the film "The Constant Gardener", released in 2005
adapted from the book by John Le Carre

"Wherever there are drug companies... testing their drugs on people who they think are expendable, you'll find organisations like ours trying to fight back. Of course, the problem is that they have millions to spend on PR... while we work with volunteers and a few donated computers. If you're gonna dig deeper, then most of us have websites. Check out Oxfam, MSF, Health Action International –"

2006

- HAI Asia-Pacific publishes *Fast, flexible and furious: The story of Health Action International (HAI) 1981-2006*.
- HAI gains accreditation at the EMEA to carry out advocacy work.
- HAI Europe sends critical comments on direct-to-consumer advertising of prescription drugs during New Zealand's consultation on this type of marketing. A number of HAI members including Joel Lexchin and Barbara Mintzes (both from Canada) send comments as well.
- HAI Europe responds critically to the European Commission's public consultation on the community's pharmacovigilance system, arguing that the current system is deeply flawed and incapable of developing into the active and responsive system Europeans need and expect.
- HAI takes part in the UN Special Session on HIV/AIDS, the first time that civil society groups are allowed to participate in the meeting itself and not just in pre-meeting consultations. HAI presents a statement on research and development.
- With millions lacking needed treatment for HIV/AIDS, HAI highlights challenges to achieving global access to antiretroviral medicines in its policy paper *HIV/AIDS: Universal access by 2010, ten challenges on the way* launched at the 59th World Health Assembly in Geneva. At the Assembly, HAI plays a pivotal role in pushing for the successful adoption of a resolution which would draw up a global strategy and plan of action for needs-driven, essential health research and development relevant to the diseases affecting those living in developing countries.
- HAI holds a technical briefing on medicine pricing issues at the World Health Assembly and publishes a briefing paper on these topics.
- Malaysia announces it will cap the prices of medicines on the WHO Essential Drugs List.
- In October, HAI celebrates its 25th anniversary with the conference "Pills, Politics and Practice: Demanding people-centered medicines policy in the 21st century".

Philippa Saunders,

Essential Drugs Project, London, United Kingdom

"A practical and visionary platform"

"In the early 1980s HAI's unique contribution was to offer a focus as well as leadership for medicines – recognising the central role of drugs in global health. It exploited the (then) new medium of networking to add effective coordination for greater impact, and it also provided a means for indivi-

duals and organisations to showcase different strands of work.

I joined HAI because it offered a practical and visionary platform that was accessible to anyone prepared to make a difference. I believe that HAI continues to have much that it is uniquely fitted to do. Its particular strength is to represent the broad agenda on medicines – regionally and globally, and in countries. It has much more flexibility than NGOs to do this, as they are restricted by having to fit corporate plans that change radically and rapidly, allowing for quick hits that cannot be sustained over time.

HAI's role has inevitably changed in an evolving policy,

technological and health context, with many new actors in the picture. It is still valuable, and could be the connecting thread linking the complex range of pharma issues that must be addressed in the future. Stronger regional capacities and focus, and well-functioning global cohesion, could make it an even more formidable player".



Nikolaou Tsemperlidis,

Coordinator, National Consumer Council and President, Consumers Protection Centre (KEPKA)

and Evangelia Kekeleki, General Secretary of KEPKA, Thessaloniki, Greece

"We joined the HAI network because we share its main principles and concerns. We get information on these issues. We use this information in our debates with other stakeholders and publish it in our magazine".

Irina Kazaryan,

Chairman, Drug Utilization Research Group Public Organization, Republic of Armenia

“It allows us to learn from experience”

“In our rapidly changing world competent actions for health are becoming more and more important as many old problems still have to be overcome and new challenges are appearing. We believe that the HAI network has played, plays and will continue to play a crucial role in promoting an active position for ensuring health for all people, in putting priority issues on the policy agenda, in implementing activities intended for improving the situation in urgent areas and

providing opportunities for wide collaboration among all of those interested.

It demonstrates a great example of an organisation that is ‘working towards a world where all people, especially the poor and disadvantaged are able to exercise their human right to health’. We have joined the HAI network as our interests, objectives and methods are common, and because we believe that being involved in such a structure as the HAI

network is very important for achieving these objectives. It allows us to be rapidly informed and learn from experience, as well as to communicate with other members on priority issues in the areas of improving access to medicines and their rational use. Some HAI books are always on our working table. Also it is important to stress that we accept and respect very much the honesty, principles and knowledgeable position that HAI always shows”.



Natalia Cebotarenco,

DrugInfo Moldova, Chisinau, Moldova

“Immediately impressed”

public health. Through the HAI network, we received the knowledge and practical skills needed to involve patients, consumers and non-medical NGOs in public health issues. In Moldova, we have now a network of health care professionals and consumers that jointly work in the public health field. HAI is one of the most powerful organisations at the international level now. HAI is a strong partner of WHO and other international organisa-

tions in most of the international projects. It is invited to all significant meetings at the international level and can influence the decision-makers on public health. But I think HAI should work more with grassroots organisations and involve more young NGOs in developing countries especially. HAI has a huge amount of experience and knowledge, trained staff and professionals around the world and can play a leading role in public health education”.

Jörg Schaaber,

Coordinator, BUKO Pharma-Kampagne, Bielefeld, Germany

“HAI has functioned as a think tank”

“BUKO became a co-founder of HAI by accident – we are still very proud of that. HAI members have provided us with brilliant information, countless ideas, inspiration and the positive feeling that we are not alone in our critique of the existing structures and that it is possible to achieve change.

HAI has enabled us to get to know so many wonderful people, have lively discussions and carry out joint action, it is an experience we would never want to miss.

HAI has done at least four things in the last 25 years that need to be highlighted:

- putting ‘the rational use of drugs’ at the top of the World Health Agenda. Nobody had done that before.
- doing the groundwork to make access to essential medicines a number one topic for many organisations and people. The early identification of the WTO as a stumbling block has been important.

- showing that drug promotion has unhealthy effects and that something has to be done about it. Noteworthy in that context is the successful prevention of the introduction of DTCA in the EU.
- making medicine prices an issue that is not limited to health insurance systems or socialists only.

The most important thing for us is that HAI, from its inception until today, has functioned as an excellent think tank where new ideas and important issues have been discussed and action started long before the mainstream had a clue about what was going on.

HAI has been and will be in the future the most important focal point for influencing the WHO medicines policy in a healthy way. Other arenas have become important too like the WTO. Hopefully HAI will continue to help merge the power of local and international health related NGOs in a fruitful way.

An important factor for the successful collaboration with HAI was and is the highly competent and dedicated staff in the offices who have implemented a lot of projects using the expertise of members and actively involving them in all stages of the process. Last but not least, the perfect and warmhearted administrative support given through the HAI Amsterdam office needs to be emphasized”.



Photo Christian Wagner

“HAI members have provided us with brilliant information, countless ideas and inspiration”

Roberto Lopez-Linares,

Coordinator of AIS (HAI Latin America)

“Setting the agenda”

“It is already known that HAI has played an important role in setting the agenda for the pharmaceutical field, calling attention to two main issues: universal access to essential drugs and the rational use of drugs. HAI did this when nobody dared to point out the factors influencing the quality of drug use and the lack of access facing millions of people in the world. HAI has the courage to stand in front of the big pharmaceutical industry and demand regulations to control its marketing practices as one of the main factors influencing the quality of drug use.

My involvement with HAI started when I used to work with poor communities in Chimbote, Peru and I had seen how the people were using dangerous and useless medicines, even for children, namely: antidiarrhoeals, tonics, brain tonics, multivitamins, etc. Even poor families wasted money on those products. HAI appeared as one of the inspiring organisations struggling for a ‘new pharmaceutical order’.

HAI contributed to the articulation of the initial findings we had made at local level, putting them on an

international level, giving the national and local work a wider perspective.

The network, gave all of us the opportunity to join with several groups fighting the same or similar problems in the pharmaceutical field. In that way, the sharing of experiences and of knowledge was very important. In a way, belonging to HAI was a way of getting a kind of a post-graduate degree on medicines and public health. Many things discussed in the network are not taught at the universities.

HAI has gone through an interesting evolution as an organisation devoted to medicines with a public health perspective. In its first period, it devoted much effort to struggle against the factors influencing the use of medicines. Those were the times of emblematic publications such as *Prescription for change* and *Problem Drugs*. In that stage, we accumulated a lot of expertise on specific areas to promote the rational use of drugs. It can be said that the activities used a consumer or ‘user’ orientation. Following this first stage, HAI added a more political tone. I would say a more comprehensive

one, not only to understand the complexity of the pharmaceutical field, but also to look for sustainable solutions, which could come from the political level. So, HAI got involved in pushing national pharmaceutical policies, etc.

A third stage of the organisation was marked by the implementation of strategies to fight for universal access to essential drugs, with the appearance of the WTO and the TRIPS agreement and other bilateral trade agreements. In this stage, fundamental human rights, especially the right to health, received great importance for HAI’s work. Access to essential drugs is now approached as a human right; a basic component of the full exertion of the right to life and health. Moreover, we understand that the proposals made by HAI involve other factors outside of the health sector. They recognize that access to essential medicines is closely linked with the rational use of drugs. And both are part of the struggle for a better world, with social justice, fighting against poverty and building democratic societies”.

Conclusion



I am delighted to be writing the conclusion to this wonderful booklet on the history of HAI Europe and the way our history fits into the big picture of HAI’s development and influence worldwide. I am grateful to Lisa

Hayes who has taken on the task of collating and editing this book with the same enthusiasm and tenacity that has been a cornerstone of HAI’s work in the last 25 years. I am also grateful to all those who have taken the time and trouble to contribute their memories of HAI past and thoughts on HAI future – and for a relative newcomer to the network it is an inspiring and humbling read. Thank you!

Two constant themes emerge from these pages. Firstly, it’s not just that HAI is a network organisation, but the way in which we all treasure and value the special character of our network. Networks come and go; often they are a loose coalition of broadly like-minded individuals with little or no real direction. At worst networks collapse in a confusion of infighting and disparate interests. But HAI is special, and I think it’s about passion.

It’s about a passion at the core of our membership that is revolted by the injustice and inequality of a world which systematically denies health for all in the pursuit of corporate interest. That, in spite of the capacity of the pharmaceutical industry to harness incredible technological achievement, in the pursuit of

markets and profits, it still refuses to put the interests of patients and consumers at the centre of its corporate plans. Of course, this doesn’t mean that HAI is ‘against’ the pharmaceutical industry, which is how we are often perceived. How could we be? Many of us owe our lives to the discoveries and inventions of the industry. However, the passion of HAI members is grounded in the belief that the power of the pharmaceutical industry, derived from technological advance and the ability to cure people of once fatal disease and injury, has been seized to provide for the interests of the few over and above the interests of the majority. It is the recognition of this core truth that feeds the passion of the HAI network and binds us together as a potent force demanding worldwide access to essential medicines and the promotion of their rational use.

That passion is as strong now as it was 25 years ago. Those of us who have been working in pharma-politics for longer than we care to remember may be more sceptical, less readily shocked – fatigued even, but I refuse to believe that the passion is diminished. Some of us may well now wear suits, carry blackberries and communicate wirelessly by videophone from airports around the world, but the passion for the task and the compassion for humanity remains as strong. Has HAI mellowed? I don’t think so. Our passion, independence, integrity, tenacity and energy are as strong as ever. Has HAI changed? Certainly. The changing character of HAI, identified by so many as the key to our success, runs throughout the comments in this book and is the other theme I want to mention.

The question is why has HAI changed so dramatically over the past 25 years? The answer is that the network is truly responsive to the shifting and amorphous nature of the forces with which we engage. Not just the pharmaceutical industry, but the entire edifice of institutions and actors which make up the dynamic of pharma-politics worldwide. We are engaging with one of the most powerful sets of interests ever known, and we cannot expect them to stand still in the face of our challenge. The point is that the HAI network has always had the capacity and competence to respond – we have an equally amorphous membership and the extraordinary combined experience of 25 years of robust challenge to injustice on which we can call, be that addressing the World Health Assembly or designing posters until late into the night. All of our activities are as valuable as each other and even the suit-wearing has its place in the armoury of tools needed to complete our work at every level.

However, for all of our passion, success, and responsive experience, we cannot afford to become complacent – HAI operates in an increasingly hostile environment; most pharma-regulators have long since been captured by industrial interests as have many governments. Healthcare professionals are increasingly less sceptical about their capture by the pharmaceutical industry and now even patients and consumers organisations have willingly come to represent the interests of Big Pharma. I am shocked that at so many so-called patient/consumer consultative exercises in which HAI participates we are alone in our independence from industry. So even many of our former allies, the patient and consumer organisations, are now under scrutiny by HAI. This has not been helped by the neo-liberalism that pervades world politics which on the one

hand makes HAI's voice of reason increasingly important. But on the other hand, it makes the battle harder, longer and more susceptible to the vagaries of funding from sources less likely to understand or want to hear HAI's message. As much as this booklet celebrates the end of an era – the first 25 years of HAI, the HAI Europe 2006 conference "Pills, politics and practice: Demanding people-centred medicines policy in the 21st century" marks the beginning of the next. For our celebratory conference, we have gathered together the biggest names in global pharma-politics from both inside and outside the HAI network. We've also brought together a number of rising stars in the world of pharmaceutical policy, people you may not know now but will hear much more from in the coming years. We've done this not just to celebrate (although we certainly shall!) but to show how the HAI collective conscience and the skills, expertise and determination of the network and its allies can contribute to improving the lives of patients and consumers all over the world for the next 25 years and beyond.

Happy Birthday HAI – and thank you for being a unique foil to the injustice of today's global health situation. Celebrate your passion and determination, your battle scars and wars won, and remember all the good times now... because tomorrow we will start work on the challenges of the next 25 years.

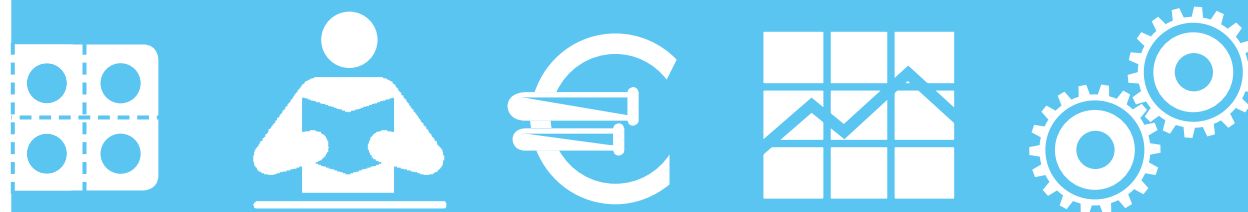
Tim Reed
Director, HAI Europe

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