



EDITORIAL

Michael Morgan

We open this edition of *Euro-Ataxia* with some very sad news. Evelina Raveggi has died. She died on 1 May 1998 – of cancer, not ataxia. Evelina was the Italian representative for EURO-ATAXIA, and both she and her husband Wais Bonaiuti have attended every EURO-ATAXIA AGM and board-meeting I can remember. Carolien Koopmans has written an eloquent obituary, but I'd just like to add my own tribute. For me, Evelina was EURO-ATAXIA, the centre around which everything orbited, and possessed of a singular warmth and humour that affected every one of us that came into contact with her.

Also by Carolien inside is her article on the psychosocial aspects of ataxia, using her own life-story to date as an example that life is life, and can be lived as well in a wheelchair as not. There are important lessons here.

If you've been following the European Press you'll probably have noticed that the medical uses of marijuana has become the focus of renewed media attention. But what of the ataxias you might say? Where do we come in to all this? These questions – and more – are addressed inside.

Cathy Arnold lives in Germany, though she originally hails from the USA. Recently her teenage son Mike had to go into hospital for scoliosis surgery, and Cathy has kindly allowed us to print her record of what happened.

On Tuesday 12 May the gene patenting directive received approval in the European Parliament at Strasbourg. Inside we print the first part of the extraordinary history of the EU Biotech Patents Directive, from its beginnings ten year ago to the present day.

Finally, as EURO-ATAXIA enters its tenth year of operation, it is perhaps appropriate to look back at what has been achieved so far. Inside Dagmar Kroebel, our secretary-general, has penned a brief outline of ten years of EURO-ATAXIA.

And just in case you forgot: the 1998 EURO-ATAXIA AGM will be held in Turku, Finland, between September 25-27.

IN MEMORIAM: EVELINA RAVEGGI

Carolien Koopmans

On 3 May the news reached us that Evelina Raveggi had died. She died on 1 May 1998 at the age of sixty-five. It was cancer, not ataxia, that killed her. After a lengthy battle she succumbed to secondary cancer, which spread to her lungs. Evelina was the Italian representative for EURO-ATAXIA, and both she and her husband Wais Bonaiuti have attended every EURO-ATAXIA AGM and board-meeting from the very beginning. This commitment, together with her age, made Evelina a kind of mother to all of us in EURO-ATAXIA. We will especially remember the

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warmth and great enthusiasm with which she welcomed her ‘children’ at the beginning of those meetings.

Evelina first developed the symptoms of dominant ataxia some twenty years ago, but only used a wheelchair for the past seven years. She and Wais had two sons. DNA tests revealed that they did not inherit the disease mutation and so the three grandchildren that the sons gave Evelina and Wais were likewise free from ataxia. Evelina was very proud of her grandchildren.

The death of sweet Evelina is a great loss for EURO-ATAXIA. Knowing Wais we’re sure that he will be strong enough to cope, and to learn to live life without his loving wife. From all corners of Europe, we in EURO-ATAXIA send our love and compassion, and wish him strength to face his loss. Our loss too.

ATAXIA: THE PSYCHOSOCIAL DIMENSION

Carolien Koopmans

In this edition I would like to respond to Michael Morgan’s earlier article on the psychosocial aspects of ataxia, in particular Friedreich’s ataxia (FA). Michael’s article was very good and I recognised a lot of aspects in my own and other ‘patient’s’ life. But in general I have a more optimistic point of view. I should point out immediately that the difference between Michael’s and my perspectives is for a major part due to the fact that he’s a man and I’m a woman. For a man life with an early onset progressive disease is more difficult, because the expected behaviour of men is more strongly defined and more compulsory than that of women. To say it in other words: the male role model is far more rigid than the female one. Abnormal or even inconsistent behaviour is more easily accepted from a woman than from a man. As the Romans said: “Semper variabilis et mutabilis est femina” (nothing so changeable as a woman).

Michael divided the career of a person with FA into three phases: childhood, adolescence, adulthood. I shall use the same division, except that I’ll split adolescence into puberty and adolescence.

Childhood

In my opinion infancy and childhood are the most important times of any person’s life. In the first 5 to 10 years of every individual’s life the fundamental basis of his/her personality is laid down. Although one’s character is partly inherited, it gets its definite form during this period. The difficulty or ease with which a person copes with problems in his/her later life are set in the starting phase of life. I agree with the neurologist/psychiatrist Oliver Sacks when he stated: “It’s more important which person gets a disease than which disease a person gets”.

My childhood years I remember as one lasting summer

holiday. The world was a wonderful place to play in. Everything new was exciting and had to be explored. Time was not so sharply divided into years, months, days, hours and seconds. As Michael states: children envisage their world as a unitary one. My world as a child surely was a whole one.

I was the youngest of four children and the only girl. But from my seventh year onwards, there was something peculiar about my movements. But the symptoms were in the beginning so slight that they didn’t strike me as negative. It was rather something positive, something that made me special. In my childhood’s innocence I felt almost proud to be different from other people. My eldest brother Erik, who was six years older than me, was moving in the same special way.

For my parents the situation was less pleasant. The neurologist refused to inform them properly. My mother told me later that in those days she asked the neurologist several times to tell her what was wrong with Erik and me. She always got a reply like: “There’s nothing wrong with those children. Nothing serious anyway.” At other times she asked: “Please doctor, don’t those children need help?” “Oh no, madam, such children are mentally so strong.”

Puberty

This stage of life was the period in which my experience differs most from Michael’s model of the FA career. And, alas, with the career of most persons with early onset ataxia.

My physical condition worsened sharply when I was twelve years of age and already in the first grade of secondary school. That was due to a traffic accident which kept me in bed for almost two months. After those two months I went back to school. The school was sited in an old building with wide corridors and stairs. It had no elevator. While my ataxia grew worse, the trouble it took to move through the building also grew.

At school the pupils clustered together in groups in the spare time between lessons, each group with a more or less fixed location around the building. I longed to be part of such a group too, because they always seemed to talk and laugh together so cheerfully. So I joined the peer groups that looked nice to me, to see which group would suit me best. It soon became clear to me that the laughter and talk that seemed so warm and enjoyable from the outside was only a thin surface, underneath which everyone was pre-occupied by their own problems (mostly problems at home). Peer groups were no more than bunches of lonely individuals, focusing on the few things they had in common.

I think Michael overestimates the importance of peer groups. Love and sex form a dark and lonely territory where everybody has to find his own way. Some find their way easily, others experience great problems. Some adore the adventures, others fear the pitfalls. There do exist teenage peer groups in which everybody

exchanges partners now and then, but those groups form no more than a minority. In general there's more know how about romantic and sexual behaviour to be gathered from books than from peers.

During the six years I was in secondary school, there was a subtle but growing variation in interpersonal communication, subtle but for me clearly noticeable. People lost their sincerity towards me, started to look at me with pity and never dared to say anything that could upset me. I was treated like I was an alien, some creature from Mars. But for me the world didn't change. The sun rose in the morning and set in the evening all the same. The birds still sang in the trees and the flowers kept on blooming. Babies were born and other people died daily, just as ever. Why was everybody making so much fuss about a problem which I had to bear? My body was my problem, not theirs. Why couldn't they just be glad they had no physical abnormality and let me be? I knew from the start that I had no choice other than to accept my burden. Even if I didn't accept it, I still would have to live with it.

My relationship with my mother was by far the worst of my problems. It seemed to me my mother first saw my physical problem and than Carolien. She was convinced that my future was going to be a very sad one, and that no boy would ever show interest in me. I must have been quite paranoid in those days: I thought I heard pity in her voice every time she spoke. Yet, to my mother I must have seemed a real bitch. Looking back, I think my mother's position was the most difficult in the family. Besides her own problems to cope with, she had her husband, Erik and me, and my able-bodied brothers Alphons and Stephan to care for. As a woman she took things more emotionally than my father, who could see the situation more rationally and from a certain distance. The fact that all of her siblings were at an egocentric age must have accentuated her lonely position.

I had a pretty lonely time during my puberty, but this surely made me no exception amongst my peers. I noticed that a lot of people thought I had no chances for the future, but I never gave up hope that there would be a place in the sun for me. I saw my FA as a purely physical problem that never interfered with my self-esteem. The degrading status with which an ataxic person has to cope was in my case not as depressing as Michael suggests, or maybe I just could withstand it better. Neither were shame, personal failure, denial and the search for identity real problems in my case.

When I was about fifteen my parents finally heard the name of the disease Erik and I had from our new GP. They were also told the expectancy for the future the diagnosis brought. I don't remember if I was officially informed by my parents or that the word 'wheelchair' just appeared in the conversation at home now and then. Anyhow, my physical state was so bad by that time that the thought of a wheelchair didn't frighten me anymore. Nothing could be worse than my contemporary state. I couldn't take a step outside the house

on my own anymore.

For my parents it would have been easier if they had known the diagnosis a few years earlier. But looking back, I'm glad I didn't know the diagnosis earlier. Apart from the psychological effects this could have had on me, I was fortunate that the thought never even crossed anyone's mind to send me to a special school for the disabled.

Adolescence

In the sixth and last grade of secondary school, I was offered the chance to study at the university in Nijmegen. This meant that I would have to live on my own in a student apartment building. I didn't have to think twice. Like all my fellow pupils, I longed to leave my parents' nest and spread my wings. If I couldn't live a life of my own, I could always return home and start leading a vegetative life. But try I must! My mother felt very bad that I denied her good cares so brutally, but I couldn't care less at the time.

Erik, who had finished his studies at a nearby university and started his professional career there, was still living at the family house and was already in a wheelchair. He and my father more or less ordered me to use a wheelchair when I started my new life in Nijmegen. They stressed the fact that I would need the mobility it offered. So the first day in Nijmegen was my first day in a wheelchair. I was a stranger in the town. I knew nobody from previous times, also no-one from my secondary school went to study there, so I felt safe in my wheelchair because I wouldn't meet anybody who had known me in my 'walking' state. And what a nice way of transport it was, being pushed and chatting at the same time! And it attracted far less attention than that awful ataxic gait.

My life as a disabled student was nice, but hard and lonely at times. Having gone through such a dreadful dead period in my secondary school years, my will to succeed had become strengthened, so I didn't give up easily. Moreover the experience of living again enabled me to stand a lot of strain. Of course I met scores of people (including students) who looked down upon a person in a wheelchair, but I comforted myself by thinking that such square-minded people weren't interesting anyway. Although it worried me sometimes that there were so many such stupid people, I usually concentrated on the nice and open-minded persons and let the stupid square-minded ones be.

I was able to make some really good friends, enjoyed my social life and even had some sexual experiences too. Just like in secondary school there were students who were very successful in dealing with the other gender, and other students who never seemed to be able or were too shy to make a pass on someone they fancied. So the fact that I couldn't always get what or whom I wanted was not extraordinary.

Adulthood

After I finished my studies I returned to my home

town to live there again. On my own that is, not with my parents and brother. I had been able to get a job at the nearby university, thanks to a social law for the employment of disabled people. Having achieved a regular job with a regular income and living in a nicely furnished apartment, I finally felt at ease. I was twenty-four then and had at last reached adulthood.

It was then that I started a serious relationship with Hans, a friend I met in my first year in Nijmegen. We married two years later. Life has brought me a lot of wonderful things since then. Hans and I are great friends and lovers. Like all married couples we do sometimes have a quarrel: it's a question of give and take from both sides – just like in all marriages in fact. Of course, the progression (what a strangely positive word for such a negative development) of my FA is a problem with which we have to deal carefully and open. Otherwise it might be a source of irrevocable tensions that might damage our marriage. But we have found practical solutions for the physical inconveniences that kept occurring. Humour is a great ally. We have always been able to laugh away the tensions the disease brings along. To other people our jokes and understatements may sometimes seem to be cruel: now and then that leads to humorous situations.

We never even thought about children. Hans doesn't care about children. I was eighteen when I got my first wheelchair and by that age I was already unable to lift a baby out of its bed. What should I do with a child? And even more important: what should a child do with a mother like me? It might be nice when the child was still very young, but what to do when the child went to school and the other children didn't want to come along and play at our house 'because you have such a strange mother'. Nowadays there are so much negative tendencies in society that parents cannot control. Hans and I simply thought it wise not to take the responsibility of having children.

My job at the university allowed me to work from home a great deal of the time, especially after I got a PC. So as my physical condition worsened I stayed at home to work for an increasing part of the week.

The most traumatic moment in our marriage came when I realised I could no longer manage to be on my own the entire day. This was a moment at which our attitudes towards my loss of physical independence had to be rethought. I thought the time had come for me to draw a line. From then on I would be the one who would be responsible for the practical consequences of the progression of my FA. Hans has his own professional career and sometimes wants to do things without me. So I arranged some professional help during the daytime: Hans is at home in the evenings and nights. And at weekends we are together most of the time.

My parents totally agree with us, so when Hans has to work late or has dinner with his colleagues, I am welcome to have dinner with them and Erik and stay at their place till Hans has finished and picks me up.

Until now my life has surely been worthwhile. During my 'struggle for life' I have found out how relative things are. It is this wisdom, I feel, that makes it easy to let the nasty things glide along your shoulders and enjoy the good things life brings. It opens the door to humour, a wonderful way for man to escape the severity of life.

CANNABIS AND ATAXIA

Michael Morgan

Most people in Europe now agree that marijuana should be legalised for medical purposes, as revealed in many surveys of public opinion across the EU area. In consequence the medical use of marijuana has become the focus of much attention. Medical use has also been used as a rallying-cry in the general campaign for decriminalisation: a major protest rally in London organised by *The Independent On Sunday* newspaper earlier this year was fronted by a line of people in wheelchairs. Yet the available evidence is patchy and so governments in Europe appear loathe to legislate. The solution to this dilemma seems transparently obvious: conduct some proper, scientific research using a strict methodology. In practice however this may not be as straightforward a matter as it looks...

Essentially it's an almost perfect example of catch 22: marijuana can only be legalised if its medical utility can be proven, but because it's an illegal drug no proper, scientific study can be undertaken which could uncover the evidence one way or the other. There are signs, however, that this barrier may be broken down in the not too distant future. Studies on the medical use of marijuana have been announced in France, The Netherlands and Germany within the past two years. In the UK meanwhile the British Medical Association wants legal permission to research this area: "We think the law should permit the research which would establish what is really the case." Throughout Europe then a new mood of genuine scientific enquiry is evident.

But what of the ataxias you might say? Where do we come in? A couple of months back I spent the weekend getting stoned. Nothing new in that you might say, a fairly common behavioural, culturally sanctioned, outlet among us hard-bitten sons of Ulster.

But what made this out of the ordinary was my means of inebriation. For this time I forsook my habitual alcohol in favour of marijuana – all in the name of scientific research of course, and for the greater good of the ataxic community.

Many ataxic people it turns out have used marijuana. A year or so ago I conducted a small-scale, informal survey via e-mail in which ataxic people gave their opinion. OK, this was hardly a rigorous scientific exercise but nonetheless the results were of more than

passing interest: some swore as to its therapeutic value (4), others were less sure (3), or even negative as to its usefulness (3). Positive replies emphasised marijuana's beneficent role in controlling the muscular problems consequent on ataxia: "Smoking marijuana seems to stop the muscle cramps in my legs, it reduces my muscle spasms, makes my speech clearer and helps me relax and sleep better." Negative ones, however, complained that taking marijuana actually worsened their ataxia: "I have sporadic OPCA, and grass has a disastrous effect – the symptoms get worse, especially at night, although very limited use per session seems OK. It's similar to alcohol – one glass of wine is OK but any more and I'm off the planet."

In other words the overall picture is confusing, and will doubtless remain so as long as we rely, as I did, on anecdotes or self-reports. What is needed is some proper scientific analyses, using proper biochemical data. Alas, although significant amounts of data are emerging on the medical uses of marijuana in an ever-increasing number of conditions, including MS, spasticity, HIV/AIDS, glaucoma, and the nausea associated with chemotherapy, the ataxias never seem to rate a mention anywhere. One valuable exception, though, is the work of *Dr. Paul Consroe*, at the University of Arizona. "A few small studies have reported that marijuana (or oral THC) reduced ataxia (and tremor) in patients with multiple sclerosis (MS), and another study in MS patients reported that marijuana made balance (ataxic 'swaying') worse. Further, most of the studies done in normal healthy volunteers have shown that marijuana is quite capable of causing some forms of ataxia.

Friedreich's ataxia is of course a quite different form of ataxia from that seen in MS patients. As well the most commonly reported 'ataxia' in normal volunteers is one of making more errors on video games and the like. However, all hereditary ataxias presumably originate from abnormalities in the cerebellum of the brain. There is one very rare hereditary ataxia call 'Refsum's disease'. This is caused by an abnormal metabolism of a fatty acid in the brain – and this fatty acid looks a lot like 'anandamide' the endogenous cannabis-like chemical found in all our brains!"

Dr. Consroe is very keen to hear from ataxic marijuana users, maybe even collaborating with members of EURO-ATAXIA. He welcomes individuals to write to him, giving their experiences, and a decision on whether a collective project on marijuana and hereditary ataxia can be developed will be discussed at the EURO-ATAXIA AGM.

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MIKE'S SCOLIOSIS

Cathy Arnold

Cathy Arnold lives in Germany with her husband and family, though she originally hails from the USA. Recently her teenage son Mike had to go into hospital, and Cathy has kindly allowed us to print her record of his scoliosis surgery. It's major surgery too and time-consuming – Mike was to spend two months in the hospital for two operations because of the large curvature of his scoliosis (75°) – but eventually worthwhile. In her own words then:

On 6 March, we checked Mike into the Universitäts Orthopädische Klinik here in Heidelberg. It's a newly renovated, state-of-the-art facility that sits above the Neckar River in the Schlierbach suburb. During pre-surgery examinations, the cardiologist found some evidence of cardiomyopathy (left septum wall thickened), but we were told that this would not preclude the scoliosis surgeries. The first of his two surgeries took place on 13 March. It took approximately 2+ hours in actual surgery. They went in via his right side and removed the sixth rib. They then removed the disks in the affected area of the spine (Mike's curvature was at 75 degrees) and packed ground bone material – from the removed rib – into the space left by the removed disks, to create an initial fusion. The post-surgery x-rays showed an immediate improvement of 50 percent! They attached a steel 'halo' to his scalp (four screws into the outer skull). His dad and I spent 2 days and nights at his side in Intensive Care. He had no problems during surgery that we knew of, but lots of post-surgery pain in the chest. They set up traction and returned him to the ward where he remained in traction for 3 weeks. Weights of increasing degree were suspended from his head and from his wrapped legs via pulleys mounted on his bed, stretching the spine. Mike had some intestinal/urinary tract problems that took a few days to improve. Then he just had to deal with laying on his back (occasionally on his side with foot weights removed) and the pain from the chest wound in his right side.

The second surgery took place on 31 March. The night before the surgery, the lead surgeon came by and explained the procedure to Mike. He told Mike that he would wake him out of the anaesthesia during the operation and ask him to wiggle his fingers and toes. Necessary or not, this extra information unsettled Mike. The next morning he went in as scheduled. Actual surgery this time took somewhat longer (3+ hrs). During this surgery, they installed the two stainless steel rods (29 cm) on either side of his spine. They removed some bone from his left hip and used this and the remaining bone material from the rib (first surgery) to complete this procedure. As in the first surgery, he was in Intensive Care for a couple of days. My husband and I were with him earlier after this sur-

gery; he wasn't off the respirator yet and was terribly pale. This time he lost a lot more blood and had to receive two pouches of replacement blood. As he was coming out of the anaesthesia, he must have asked me a dozen times if he had wiggled his toes and fingers. He did appreciate having the 'headgear' removed. (This was done during the surgery.) When he was returned to the ward, he again had a few days of intestinal/urinary tract difficulty. It took a couple of weeks to get to the point where they put him on his feet and started making him walk. He had a lot of pain in his legs and feet, and had lost a lot of muscle tone. The last week or so was mostly physical therapy and walking with the assistance of a retro-walker (supports the patient from behind and brakes when the patient leans back). A sure sign that Mike's health was returning were his jokes about the staff having eaten his sixth rib for lunch and telling people that the scars on his forehead – from the 'halo' screws – were where his horns were coming in. Even so, after almost two months in the hospital, Mike was so sick of hospital food and the daily hospital routine, he was thrilled to be released on 29 April. We thanked the wonderful and competent hospital doctors and staff (leaving big thank-you boxes of chocolates with both the Intensive Care and ward staffs). Then we went to celebrate Mike's release with lunch in a local restaurant. Yes it is great to have Mike home. Even our Siamese kitty is glad that we're all together again.

THE HISTORY OF THE EU BIOTECH PATENTS DIRECTIVE (part 1)

Michael Morgan

On Tuesday 12th May, almost ten years after its first introduction, the EU biotechnology patents directive – or gene patenting directive as it is more commonly known – at last received approval in the European Parliament at Strasbourg. The 'common position' advanced in the Council of Ministers' draft was approved without further amendments. A Green alliance had introduced a raft of such amendments, which, if approved, would have effectively crippled the emerging Biotechnology Industry in Europe. In the end only 78 MEPs voted in favour of the amendments, 432 voted against and there were 24 abstentions. This is however not the final act in the drama as the directive will now go back to the Council of Ministers for their final approval, and will then have to be transferred into national law in each EU member state. But it is the endgame in this struggle, yes. It is also important symbolically in that it signals renewed EU support for the Biotechnology Industry, whose confidence in Europe as a base of operations had been dented by initially successful spoiling tactics mounted by the Greens which derailed the directive at its first reading in 1995. A lot of effort went into countering Green propaganda, and a

lot of money was spent by both sides in this contest. EURO-ATAXIA has always supported the Biotech directive from its inception, precisely because it sees Biotechnology as an important ally in the war against ataxia (and other genetic diseases). Basically it views it as a delivery system, translating the findings of pure genetic research into practical therapeutic products. For us – as for many others – the Biotech directive was seen as a technical piece of legislation, aiming to harmonise existing national law throughout the European community, and thus providing the necessary framework within which a truly European Biotech Industry could develop.

At which point enter the Greens. By the mid-1990s Greens had come to view Biotechnology as the great Satan of the modern world, a threat not only to the present but the future of mankind, the planet and anything else left over. In this scenario Biotechnologists were motivated by greed: corporate, capitalistic greed, nothing more. Only Greens were pure. Green animus against biotechnology was already known, but in 1995 it hardened into specific opposition when the Greens in the European Parliament launched a surprise attack on the Biotech directive, tabling 70 amendments, effectively putting the whole thing into stall. The Greens were able to mobilise support on two points. First the directive was a complex piece of legislation, requiring detailed study, but the Greens were able to put the issues into a highly simplistic frame of goodie greens versus biotechnology baddies and so tug at the MEPs heartstrings. Second most of the European public are genuinely anxious, even fearful, about biotechnology – which they don't really understand. Capitalising on these fears and pitching on emotion gave the Greens an easy victory. No doubt they were helped by it being late at night and the MEPs being tired and emotional. Also the European Parliament probably contains the highest density of pompous arseholes per square metre on the planet, and such people can easily be swung by sheer rhetoric. That this is so can be seen by the fact that some of the MEPs who voted for the Greens' amendments actually owe their lives to biotechnology, Mary Banotti of Ireland being one. The result was that the original directive was stalled, suffocating in an avalanche of amendments. The Biotech Industry held its breath. Support groups of people with genetic disabilities held their breath too. Only the Greens had reason to celebrate...

(To be continued.)

TEN YEARS OF EURO-ATAXIA

Dagmar Kroebe

As EURO-ATAXIA enters its tenth year of operation, it is perhaps appropriate to look back at what has been achieved so far. EURO-ATAXIA is very much a creature of its time, and that time has been one of the

most exciting for medical science and research. Revolutionary advances in the science of molecular genetics over the past two decades have delivered the technology that has, in turn, revealed key insights and information on hereditary ataxia. The genetic location of many dominantly inherited spino-cerebellar ataxias, SCA 1, SCA 2, SCA 3, are now known and the molecular net is closing fast on SCA 4, SCA 6 and SCA 7. Most exciting of all, the location of the Friedreich's ataxia gene was discovered in 1996, and ongoing research is fast unravelling its biochemical basis. By the end of the century we could be announcing the first effective treatment for Friedreich's ataxia – a position unthinkable only a few years ago. EURO-ATAXIA is both proud and honoured to have played its role, however small, in supporting and facilitating this research.

EURO-ATAXIA – short for the European Federation of Hereditary Ataxias – was first set up in Belgium in September 1989. It is formed from the numerous national voluntary associations that support people with hereditary ataxia across the European continent. It remains situated in Belgium, where it is registered as a charity under Belgian law, and is ran from Overijse, a small village just outside Brussels.

EURO-ATAXIA's current membership reflects its international make-up: groups and individuals from Belgium, France, Spain, The Netherlands, Switzerland, Germany, Sweden, Finland, Great Britain, Ireland and Italy work together to present a common European front in the war against ataxia. To ensure all groups in all countries are equally represented in EURO-ATAXIA representatives from each are invited onto the EURO-ATAXIA board – the managing council of the federation – which meets usually twice a year. As well of course the Annual General Meeting of EURO-ATAXIA is held each year normally in different locations throughout Europe, the intention being to bring the federation face to face with ataxic people everywhere. This year, 1998, the AGM will be held in Finland – our first foray into Scandinavia, although previous locations have included Belgium (twice); Italy; England; The Netherlands (three times); Germany; Ireland.

The purpose behind EURO-ATAXIA can be summed up in one word: co-operation. EURO-ATAXIA exists to encourage co-operation between national groups dealing with ataxias, also to co-operate with national organisations and institutes whose aim is to help all people with neuromuscular disorders. EURO-ATAXIA is keen to facilitate co-operation with, and co-operation between, all scientific and medical bodies concerned with research into hereditary ataxia. Help with fund-raising on an international level, the handling of bequests and donations from people wishing to help fight ataxia, whether on the scientific or welfare fronts, is also available. EURO-ATAXIA also co-operates with many disabled groups in Europe to promote the equal oppor-


tunities of ataxic people within society. Ataxic people are disabled people and suffer much the same discrimination and disadvantage in life. EURO-ATAXIA is committed to help change this for all ataxic people, and for all disabled people too.

EURO-ATAXIA is therefore committed to:

- monitor and support scientific and medical research into hereditary ataxias.
- to centralise information on all aspects of scientific and medical research and to ensure its communication to all member nations of EURO-ATAXIA.
- to encourage and improve contacts between all members of the scientific and medical research community involved with hereditary ataxia and to encourage and to improve the steady flow of information between them.
- to encourage international collaboration between all national associations for people with hereditary ataxias, and to examine and campaign on all other issues – social, political, cultural, welfare – which affect the well-being of people with hereditary ataxias, and encourage the exchange of information on these issues.
- to work with or be affiliated to other European or international organisations to promote the well-being of people with disabilities – particularly people with neuromuscular disabilities.

EURO-ATAXIA is representative of, and in the main run by, ataxic people. The planning and implementation of every activity of EURO-ATAXIA is realised by people with ataxia or people who have been mandated by ataxic people. The board is composed in its majority by people with ataxias. And one of the expected results is that all our activities are monitored by the board. Our aim is to involve the entire ataxic community in Europe in our operations, as well of course to facilitate and help those in the research community making common cause with us in the fight against hereditary ataxia.

**CLOSING DATE FOR
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