



### EDITORIAL

Research into the ataxias continues to gather momentum as we will report inside. The location of 4 ataxia genes has been discovered, and the search for the FA locus narrows between ever smaller limits.

The 6th EURO-ATAXIA AGM, held in Munich from October 7th through 9th, focused for a great part on the ethics of prenatal and prediagnostic testing. In our next issue we will publish some articles on this subject. Although there is much importance in these discussions, for the average ataxic person the problems in living with ataxia come first. We therefore publish inside a number of articles written by different ataxic people on issues they face in everyday life: living with diabetes, yoga and relations.

We also include articles on the position and functioning of EURO-ATAXIA itself, and the problems that arise in those European states where questions of nationality still have to be resolved.

Finally the editors wish to apologize to Peter Cordwell from FAG for omitting in the last issues his name from the list of board members.

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### THE INSULIN-PUMP

Insulin-dependant diabetes (officially *diabetes mellitus* type I) is more prevalent amongst persons with Friedreich's ataxia than amongst others, albeit there is no causal connection. That is to say, not every person with Friedreich's will 'automatically' be afflicted with diabetes as well; only chances that he/she will develop it are somewhat higher.

In my case diabetes was diagnosed when I was 35, in the beginning of 1985. The hospital concluded that I could not be regulated with less than two injections a day. As I could not inject myself on account of my limited dexterity, I switched to an insulin-pump. Next year I have been wearing one for ten years, so I acquired a lot of experience with it. Which is the reason the editors asked me to write some of that down.

#### Insulin-pump: basal and bolus

An insulin-pump is a battery-driven electronic device the size of a packet of cigarettes. Via a tube it is connected to a needle permanently inserted into your belly. It is generally worn on some kind of band encircling your middle – in my case attached to my belt during the day and at night in a knitted bag strapped to my body. Through the tube the pump delivers about 20 times per hour a tiny quantity of short-working insulin, the so-called basal rate. If that basal rate, which can be pre-set, is adjusted alright your body gets 24 times 20 (=480) deliveries of insulin per twenty-four hours, a dose which more or less equals the metabolism of the body-at-rest, *i.e.* without eating. Such a dosage spread throughout day and night is vastly superior to one or two injections with long-working insulin; with that, the pump is a godsend for people who are quite unstable in their blood-sugar levels and who go from too high to too low all of the time.

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A second characteristic of the pump is the so-called bolus, the units of insulin you need to have before meals. The pump delivers those through the tube after you have pressed the bolus-button a few times (accompanied by a visible and/or audible 'click'). For me, this was the actual reason for switching to an insulin-pump: instead of unpacking syringe and needle, messing around with a flask of insulin, filling the syringe, removing articles of clothing, folding the skin, injecting and dressing up again, a few clicks suffice. And as long as you don't eat, you don't need a bolus: you can move your meals anyway you want or even skip one entirely. The opposite is possible too: when eating more than your diet allows or taking an extra meal altogether, you just click the necessary units extra (you can do this even in the middle of a noisy restaurant).

### Self-testing

The use of an insulin-pump should go hand in glove with testing your blood-sugar levels by way of drawing a drop of blood from your finger and measuring the blood-sugar content with an electronic tester. Some people are quite fanatic about that (they test themselves a few times every day), but I take a more relaxed attitude: only to check if everything is still alright or to test special situations. It boils down to my creating two or three times a month a so-called daily curve, *i.e.* one test before having eaten anything and three times after each meal. The pattern emerging from those tests is the basis for my four-monthly consult with the internist.

### Need for knowledge

Because you are regulated more sharply, you constantly have to be prepared for hypoglycaemic episodes (in my case at least once a month). Combined with the possibility of clicking extra, use of an insulin-pump supposes quite a lot of knowledge about diabetes in general and food in particular (you have to know, for instance, that rice contains twice as much carbohydrates as potatoes, that one banana equals two slices of bread and a piece of apple-pie even four). Well, acquiring that knowledge does not have to be much of a problem: the Diabetes Association in your country can provide you with (rather inexpensive) brochures on various subjects relating to diabetes. There may even be one – as in Holland – especially dedicated to the insulin-pump. Required reading for anyone considering the switch!

### Disadvantages

What remains is pointing out two major disadvantages: the (further) restriction of your freedom of movement and the permanent needle in your belly. As for

the first: you're stuck with the pump day and night and you cannot take a swim or a shower with it. However, everyone will find his/her own solution. Mine is the next. On the day I go for my weekly swim (at 6 p.m.) I disconnect the pump in the morning and switch to insulin-pens: instead of the pump's basal I take 18 units of long-working insulin and before each meal a few units of short-working insulin. Then the night after my swim I go to sleep without the pump, take a shower next morning, and re-connect the pump afterwards. In this way I am 'free' for 24 hours a week.

As for the permanent needle in your belly: the idea is a lot worse than the actual experience. Normally you don't even notice it, even when bowing over or pressing your belly. Insertion of it – in my case once a week – is something you'll dread at first, but you'll get used to it quite fast. So fast that after a while you'll start to wonder what all your worrying was even about.

### Conclusion

All in all the advantages vastly outnumber the disadvantages: with the sharp and stable regulation the pump effects you feel vigorous and energetic (and not so wretched and sluggish as a result of blood-sugar levels that are constantly too high). In my case I'm glad with the pump *twice* a week: one time when I get rid of it (nice and free) and one time when it goes back on again: then I too go 'back to normal'.

*Erik Koopmans*

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## NEWS & CONFERENCES

### ASHG Conference, 18-22 October 1994

The American Society of Human Genetics will hold its 44th Annual Meeting in Montréal, Québec, Canada, beginning on Tuesday, October 18, through Saturday, October 22. Scientific and all other sessions will be held in the Montréal Convention Centre/Palais des Congrès de Montréal. Depending on when this issue of *Euro-Ataxia* comes out, you will either just be able to get to this or miss it by a whisker.

**The Social Context Of The New Genetics** was the title of a day-long workshop held at the annual conference of the British association in Loughborough, UK, on 6 September last. Although this is past news now we will endeavour to report the findings in *Euro-Ataxia* as the social and psychological side of the new genetic technology is very important, especially for those of us on the receiving end of these applications. In May 1994 the **European Directive on the Legal Protection for Biotechnological Inventions** was dis-

cussed by the European Parliament. Central to the debate was the question of whether human gene sequences should be patentable – an issue which has attracted much interest, even passion, it must be said. A draft drawn up by the EU Legal Affairs Committee recommended that human gene sequences should *not* be patentable, and this seems to have been accepted by the Parliament. However the debate was cut-off in mid-session so we're all still pretty much in the dark. Even now, six months later, the picture is still confusing. The latest reports indicate that the EU Legal Affairs Committee is again preparing a draft resolution, more or less on the same lines as before, though when this will be presented to the European Parliament is anybody's guess.

Meanwhile *Euro-Ataxia* goes hi-tech. The Editor now has an e-mail address, and can be reached at:

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*Michael Morgan*

## SCIENTIFIC ACHIEVEMENTS ON HEREDITARY ATAXIAS: STATE OF THE ART IN 1994

### Friedreich's Ataxia (FRDA)

- a. the candidate chromosomal region containing FRDA locus has been narrowed to:
  - 1.000.000 base-pairs in 1993;
  - 450.000 base-pairs in 1994;
  - 300.000 base-pairs in 1994.
- b. some FRDA candidate genes have been described:
  - X11 in 1993;
  - X104=CSFA1 and X123 in 1994.
- c. clinical implications of the molecular work:
  - prenatal test;
  - suggestion that onset may occur after 20 years in some patients and that, even though rarely, knee jerks may be retained (expansion of the Friedreich's ataxia phenotype).

### Familial Isolated Vitamin E Deficiency (FIVED)

- a. lack of liver alfa-tocopherol-binding protein (ATRP) is the proposed biochemical fault in FIVED (1992);
- b. the FIVED chromosomal candidate region spans 4.800.000 base-pairs on the long arm of chromosome 8 (1993);
- c. the gene encoding for ATBP is located on the same chromosomal region and represents the FIVED candidate gene (1994).

### Autosomal Dominant Cerebellar Ataxia (ADCA)

at least four genetic entities have been identified within ADCA:

- a. **Spinocerebellar ataxia type 1 (SCA 1)**  
SCA 1 gene maps to the short arm of chromosome 6 (1974);  
SCA1 is caused by an expanded, unstable trinucleotide cytosine-adenine-guanine repeat (1993);  
SCA1 gene has been cloned, it spans 450.000 base pairs and encodes for a protein called ataxin-1, whose function is unknown (1994).
- b. **SCA2**  
SCA2 gene was assigned to a 35.000.000 base-pair interval on the long arm of chromosome 12 (1993); the chromosomal candidate region spans 6.400.000 base-pairs (1994).
- c. **Machado-Joseph Disease (MJD/SCA3)**  
the MJD gene has been mapped to a 29.000.000 base-pair segment on the long arm of chromosome 14 (1993);  
the chromosomal candidate region spans 3.000.000 base-pairs (1994).
- d. **SCA4**  
SCA4 gene has been localised to the long arm of chromosome 16 (1994).

### Dentatorubropallidoluysian Atrophy (DRPLA)

DRPLA gene has been mapped to the short arm of chromosome 12; the identified gene contains an expanded, unstable trinucleotide cytosine-adenine-guanine repeat in Japanese families (1993); DRPLA mutation has also been found in European families (1994).

### Clinical implications

Prenatal and predictive tests by direct mutation analysis in SCA1 and DRPLA and by linkage analysis in the others.

*Alessandro Filla and Sergio Coccozza*

## RELATIONS AND ATAXIA: A DIFFERENT VIEW

I feel obliged to react to Michael Morgan's article about sex and ataxia. I think Michael's view is much too sombre. Please don't regard my criticism as a personal attack on Michael, but as a criticism on the Western way of thinking. Today the way of thinking in our society is guided by science. Science consists at the moment of a lot of detailed theories, but lacks an overall point of view. Strong support for this opinion is coming these days from the neurosciences – the part of science that studies the functioning of the

brain – especially from the research-group of Gerald Edelman. Lately there was a BBC-documentary on the Dutch television about Edelman's work in which he was called 'the new Darwin'.

The neurobiological findings of Edelman indeed have great implications for the philosophical and psychological field. I have just finished my book *Het emotionele vacuüm; over de kloof tussen leven en wetenschap* (The emotional vacuum; on the gap between life and science), in which I have tried to work out some of these implications. In my book I have tried to make clear in a balanced and lively way what's wrong with our reasoning. I have used the stories of handicapped and autobiographic tales as extreme examples of bad developments in our society.

Today we live in a world that is completely confused. When you look at the history of life on earth as a tv-documentary of an hour, the *homo sapiens* appears on the screen only in the last two seconds. And look at the mess he has made in such a short time! Notice all the wars, violence, the pollution of the environment, the refugees, the unemployment, the hunger, the loneliness in the big cities and so on.

Most people seem to believe that the value of life lies in material objects and good appearances. An overwhelming lot of people think that the goal of life is having a good career, a high income, a pretty wife to make other people jealous and good-looking and bright children to show the world you have made a success of your life. If you grow up with such ideas, what is left of life when your body develops a progressive handicap? Not much, I suppose. This is what's happening all the time: people who seem to lose all interest in life when some physical disorder comes into play. Living that becomes surviving. When you accept these general ideas in society and believe that they are true, you will lose all self-respect when you get an ataxia. A very dangerous way of thinking because if you aren't careful it might turn out to be a self-fulfilling prophesy. When you start to behave according to your own negative expectations, they might indeed come true.

The usual way of thinking, just like the scientific way of thinking, is dominated by causal relations. In a view of the world in terms of cause and effect, all developments can be predicted. Regarding life in such a strict manner leaves little room for hope. Because what is hope? Hope is the belief that things don't have to develop like expected by the scientific theory or the statistics, but might work out in another way.

But is the value of life really enclosed in external matters and outward looks? Is the sense of living somewhere outside yourself? Just because everybody says so doesn't mean it is true. Let people talk and think like they wish to think. Don't care about stupid,

square-minded people and go your own way. When square people react like you are no longer one of them because your movements are not identical to theirs, you shouldn't believe them. Just ignore them. It might be difficult in the beginning, but after a while you'll realize that not everybody is thinking in such a preoccupied way. Don't give up too soon, because there are people who don't think so square and accept you as you are. You should give those warm and friendly people a chance to come into your life.

When I was a child and FA started to develop, the symptoms were in the beginning very light. So light that they didn't really bother me; they only made me special. As a teenager my physical problems worsened, but I still felt I was Carolien. The world in which I lived was the same old one too; the sun still rose every morning and went down every evening. But what puzzled me very much was the fact that everybody treated me like I had become somebody else. Somebody who had no future left. I could see people think that all I could hope for was a nice furnished room and the loving care of my parents. No-one ever spoke out those terrible expectations (for them: certainties) aloud; I really lived in an emotional vacuum. I felt suffocated.

During the last year of my secondary school I was offered the chance to start a study history at the university of Nijmegen, a town near the Eastern border of the Netherlands, and live on my own. I simply had to take that chance, see for myself what life could offer me. If I failed, if I couldn't manage on my own, I could always return home and start vegetating the rest of my life. But at least I had to try.

When I went to Nijmegen, I had to start making use of a wheelchair. That caused me little trouble. Maybe because the last year that I went to school was so awful; being unable to walk alone or to ride bike, I couldn't go anywhere, and having little friends, I was bored to death. What a relief it was having a wheelchair, and being able to go to the pub with my fellow-students! I was 18 then. One of the reasons why I felt so relaxed on my first day in a wheelchair was the simple fact that I didn't spend it in my home-town. I spent it in a town where I didn't know anybody, so I couldn't meet anybody who knew me from the time I was *not* sitting in a wheelchair. (Was I more bothered by the reactions I feared that other people could show than by the fact that I had to use a wheelchair?) And it was comforting to notice that a wheelchair attracts a lot less attention than that awful gait of the years just before the wheelchair.

That Michael's vision is more pessimistic isn't hard to understand, at least in my opinion. Michael and I have one big difference: Michael is a man and I am a woman. Finding a partner seems to be less difficult

for a woman with FA than for a man with FA. When you look at all the FA'ers who have found a partner, you'll see that most of them are women. I think it is not just because sexual activities ask more physical effort of a man than of a woman. As Michael pointed out, the physical problems that may arise when the male FA'er gets older usually don't play in puberty and adolescence, the time in life when most partnerships come into being. I think that an important aspect is that in our society the male role is stricter than the role for a female, or to say it in other words, the expectations of how a man will be and behave are much more compulsory than the expectations regarding a woman. And because the stereotype is stronger, it is harder to overcome. Besides, the male brain seems to operate in an other way than the female brain.

Although it was sometimes a bit hard and lonely – even a lot of students being square and superficial – I spent six wonderful years in Nijmegen. After I finished my studies and went living on my own again in my home-town, the town where my parents lived, Hans – one of the people I met on my first day in Nijmegen, on my first day in a wheelchair – and I got steady. At the moment we're married for almost 12 years. We have a very good relationship and a great marriage. We have never thought about having children and never missed them. Life has given me more than I dared to hope when I was still walking.

*Dr. Carolien Koopmans*

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## YOGA

1993 was most definitely not a good year for me, so I was in dire need of a breathing space when I saw the opportunity to spend a few days at the Yoga For Health Foundation at Ickwell Bury. Set in rural Bedfordshire, but only seven miles or so south-east of Bedford itself and twenty miles north of Luton Airport.

The centre is an impressive sight, set within a country manor dating back to the seventeenth century and beyond.

Ickwell Bury is the nerve-centre of a world-wide organisation with numerous international branches. Germany, Denmark and, yes, Ireland were represented when I was there. The home-front was represented by a strong contingent from Macclesfield and District, together with a sprinkling of individuals from places as far apart as London and Darlington. Most of those present already practised or belonged to a yoga group. Going to 'The Bur' was hence much in the nature of a special treat for enthusiasts.

The Centre has been running MS courses since 1978 and about two thousand disabled people have made use of its facilities since then. There are a number of programmes: a short course spread over five-days and a three week intensive stay. Moreover, although billed as a specific 'yoga for MS' course people with other neuromuscular diseases were welcome too (which is of course how I got on it). The price for a five day stay was £195, which worked out at slightly under £40 a day – steep enough I thought but then, maybe that's me being mean. As well as the yoga the price included three (vegetarian) meals per day and continual daytime care. Overall conditions were comfortable rather than grand with communal bedrooms (although individual rooms were also there for the asking, I was given to understand). Entertainment at night consisted of conversation, reading and trivial pursuit for the less inhibited. Being on my best, unloutish behaviour I didn't ask where the telly was either – it didn't seem that sort of place.

The daily regime consisted of a one-and-a-half hours yoga exercise routine each morning. The yoga took place in a gym (though they probably didn't call it that) located in one of the side buildings. This was comfortable and airy, and came complete with lift for wheelchair users and loop system for hearing-aid wearers. This was followed by a half-hours meditation session in the lounge. In the afternoon a lengthy talk with questions & answers was given by Bill and Joy, the resident yoga tutors who 'led' the MS course throughout the week. Herein the philosophy of yoga was expounded – a bit more than Zen, vegetarianism and eastern esotericism it should be said – although, of course, it was presented on a take or leave it basis, as something distinct and separate from the mornings exercise programme. The rest of the day remained open, acres of free space set aside for meditative contemplation – although, in practice, participants tended to head out the back for coffee, conversation and a discreet fag.

For the last session Howard Kent, Director of the centre and the leading international figure in the world of yoga, joined us and gave an excellent talk on the value of yoga for people with MS and other neuromuscular diseases.

My suspicions tend to be roused when I hear of something being specifically targeted at people with MS. MS is such a variable condition, often on a daily basis, that it's quite easy to make grandiose claims about the efficacy of all sorts of treatments simply on the basis of temporary upswings in the condition – which may or may not have anything to do with any extrinsic cause. To be fair, the Yoga For Health Foundation were careful to avoid making any such claims. Their role was not to enact miracle-cures or to make

specific claims regarding treatment. Rather, as Howard Kent explained, Yoga For Health Foundations role was to offer us the tools that could be utilised by us to fight our particular condition – the onus was always on us. By ‘tools’ was meant, not simply the benefits of yoga as a physical exercise programme – which is unquestionable – but also the promotion of a positive approach to the everyday stresses inherent in the disabled lifestyle. All of us with neuromuscular disabilities have to find ways of coping with the gradual loss of control that is the most pronounced feature of living with a progressive disease. This loss of control may originate physically but it becomes much more of a psychological pressure as time wears on. People with MS are especially prone to this because of the variability in condition that MS brings: from walking unaided to being bedridden within a single week gives the self little space to develop any compensatory strategy. For people with ataxia the decline is more gradual, yet inexorable. It's a special kind of stress, not sudden and traumatic, but a constant and continual strain. Daily life becomes problematic. Hence the appeal of yoga in particular is that it offers a means whereby we can re-assert control and in so doing, re-assert ourselves. Ultimately, the value of courses like these resides more in the psychological strengths gained rather than the purely physical benefits made. This ‘charge of positivity’ is probably the chief benefit of a stay at Ickwell Bury. And, of course, it's good for your body as well.

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## ATAXIA IN A DIVIDED EUROPE

EURO-ATAXIA recommends ataxic people in Europe to join or form their own national group and in that way become part of EURO-ATAXIA. This is no more than following one of the key assumptions behind the European Union – that of a federal structure built onto that of the nation-states which support it. It may seem odd, even paradoxical, that one of the most deliberately *international* of structures – the EU – should be tied so closely to *national* interests, but history shows that nationalism is still very much a live force in the modern world.

For the most part the underlying nationalism of the EU causes little problems; most of the European population live in homogenous, stable communities, untroubled by questions of national identity or allegiance to the state.

For some populations however unresolved questions over national identity simmer on. Sometimes this can break out into bitter conflict, sometimes *ad hoc* compromises can be reached and tension diffused.

All of which must seem far, far removed from the world of ataxia and ataxia research, so what possible relevance could this have for us you may ask? Actually, quite a lot.

Although ataxia researchers are formally committed to sharing information on an international basis, we know in practice that a good deal of national rivalry and competition does in fact go on. Whilst most of this is benign – acting as a spur to individual research drives to ‘see who gets there first’ for example – it could become harmful if findings were withheld from rival ‘teams’ of researchers in ‘foreign’ countries. But of course reputable scientists are above all this sort of petty-minded chauvinism – aren't they?

However it's in the organisation of ataxia self-help groups that problems may emerge. There are several ataxia families in the former Yugoslavia, though in which ‘ethnic’ homeland we don't know. All we can do is pray for their safety in these most terrible of times. On a much lesser scale of violence is the long running conflict in Northern Ireland. Therein two relatively equally-sized communities (British/Irish) vie for supremacy or at least freedom from domination from the other. Within this situation voluntary groups walk a tightrope, careful not to offend either ‘side’ by maintaining a strict neutrality.

Originally the Northern Ireland FA Group was set up as a social support group treating all people from whatever community with equal respect. This changed, however, when NIFAG became integrated within the ‘British’ FAG. This “We are *British*” identity means that *Irish* people with ataxia in Northern Ireland now feel themselves excluded.

Belgium manages its deep division between its French and Flemish communities by having two sets of almost everything at almost every social level. Whilst this often means added bureaucracy, it makes for an effective way of defusing a potentially lethal conflict – better too many forms to fill in than too many graves. Thus there are two ataxia organisations in Belgium, corresponding to the French/Flemish divide: Association Belge de l'Ataxie de Friedreich (ABAF) based in Bouffioulx in the south-west and Vlaamse Liga voor Ataxie van Friedreich (VLAFA) based in Brugge in the heart of Flanders. One problem that is caused by the EU's nation-state mania is the

necessity to have a single EURO-ATAXIA representative from 'Belgium'. This is got round by having a compromise candidate, which works alright but is far from ideal.

The opening up of Eastern Europe in 1980s has caused EURO-ATAXIA to look eastwards to find new ataxia communities. But it has also meant problems for 'national' groups. Since re-unification in 1989 Germany has seen a growing tension between 'Ossies' and 'Wessies'. Both are culturally distinct, a distinction which can even be seen in ataxia organisation. Günther Oesterle, of Deutsche Heredo-Ataxie Gesellschaft, has welcomed new members from Dresden, Leipzig and Berlin. A general point about Eastern Europeans, however, is that they are more inclined to look to the state than to form a self-help group for themselves. Given their recent history this is understandable. There is little tradition of *Bürgerinitiative* – citizen's action – as independent action would have been viewed with suspicion from the totalitarian state. A visit from the *Stasi* might have been the result. Hence Eastern Europeans tend to join EURO-ATAXIA as individuals, not as 'national' groups.

The overall impression is that, paradoxically, it is the EU itself which insists that everything be organised on the basis of the nation-state, and this as we have seen above is by no means an ideal solution for those countries whose populations are divided amongst themselves.

*Michael Morgan*

## GIG ADDRESS CHANGE

The Genetic Interest Group (GIG) in the UK has recently moved its office into London. It's a fact of life that London is the place where most things are happening in the UK and moving into the Capital is a sign of increased confidence.

Meanwhile GIG continue to exert influence and plan services on behalf of everybody with a genetic disease. Their well-attended 'Interface' programme of public lectures promises to deal with important subjects, such as the provision of genetic services and genetic counselling. Full details of GIGs 1995 programme is available from their new office:

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## UK GENETICS UNDER ATTACK

Thatcher might be gone, but her (evil) spirit lives on. The re-structuring of the NHS in the UK along lines dictated by market economics has seen not a promised renewal but the progressive collapse of what was once a world renowned Health Service. Now genetics has felt the blows, so much so that no less than *five* Professors of Molecular Biology in London have quit. Among them is Professor Bob Williamson of St. Mary's, Paddington, one of the leading international figures in genetic research, acting Head Of Ataxia Research in the UK, and a pioneer of gene therapy with cystic fibrosis sufferers. He will leave to take up position as Professor of Genetics at Melbourne, Australia. Other scientists who are going include Professors Martin Bobrow, Kay Davies, Keith Johnson and Lucio Luzzatto, who commented: 'what the government is doing to the NHS is suicidal. They are repudiating its research base.'

*Michael Morgan*

**CLOSING DATE FOR THE  
NEXT ISSUE**

**1 FEBRUARY 1995**



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