I\n\nT WAS the story which propelled narcolepsy into the headlines around the world in 2011 but thanks to a number of unanswered questions, the subject of Pandemrix is set to keep the condition there during 2012.

Pandemrix was the vaccine used to prevent H1N1 Avian Influenza and at the end of 2010 the first news came out of Finland suggesting a link between Pandemrix and narcolepsy in people under the age of 18.

This was quickly followed by reports from Sweden and Norway and increased numbers in France, Ireland and Iceland.

It wasn’t until April last year that some real facts and figures began to emerge and then it became clear that a link existed between giving under-18s Pandemrix and narcolepsy.

By July the case was proved to the extent that the European Medical Agency requested all Pandemrix packaging carry a warning stating that the vaccine should not be given to those under the age of 18.

In the UK the NHS provided about one million doses of Pandemrix to those below the age of 16. Using the now accepted figures of eight extra cases per 100,000 this means that the UK should see an extra 80 children develop narcolepsy as a result of taking Pandemrix.

We do know that all those children so far tested that developed narcolepsy after taking Pandemrix had the HLA subtype DQB1*0602 – over 90 per cent of people with narcolepsy have this genetic marker while 20 per cent of the population generally have it.

This suggests the children had the genetic propensity to develop narcolepsy and some could well have gone on to develop it anyway. The truth is we will never know.

Early results back from Finland show that 25 per cent of those tested had antibodies to the adjuvant squaline, which is found in Pandemrix. It is used in vaccines to boost its effectiveness.

We also found out that a mercury derivative called thimerosal was found in Pandemrix to prevent a build-up of harmful bacteria while the vaccine is stored. Both thimerosal and adjuvanted vaccines are banned in many countries, including the United States.

Today we still have many questions unanswered, with three that stand out:

1. Is the narcolepsy suffered by children who had Pandemrix, the same as ‘standard’ narcolepsy? Many doctors believe that the condition has subtle differences in those who developed narcolepsy after taking Pandemrix and we need to find out why that might be.
2. How long will it take the government to properly support those families affected by Pandemrix?
3. Is it safe for people to have vaccinations that contain substances banned in other parts of the world, namely thimerosal and adjuvants?

On the last two points Narcolepsy UK is clear. The charity is pressing the Department of Health to meet its liabilities as quickly as possible. We are also pressing the government to look again at the application of adjuvants and thimerosal to vaccines.

Most if not all the vaccines available in the UK are available in the USA where they will not have an adjuvant present – ask your doctor to buy in a stock for your children.

Of course this will not help the families of children who have already developed narcolepsy and we will redouble our efforts in 2012 to get justice and support for them and the entire population of people with narcolepsy.
Orexin research continues to be vital for narcoleptics

ONE OF the most interesting developments in research during 2011 has been the increasing number of areas that orexin production (hypocretin) has an impact on.

In December 2010 we read the first of a number of papers that showed a lack of orexin causes a lack of vigilance and an increase in risk taking. Then we discovered how a lack of orexin can cause you to gain weight, make you more susceptible to changes in temperature and how bright light can cause people with low orexin levels to find it difficult to retain information.

For us the most important paper of the year did not arrive until November and it came from Neuron. Trying to find out why people who eat little get fat, scientists at Cambridge discovered it was down to orexin production.

Earlier in the year we had published information on how orexin controls ‘brown fat’ which controls body heat. Without orexin you only create standard fat and it becomes more difficult to have long term weight loss.

Cambridge took this information to the next step and started to compare the actions of different nutrients on orexin production.

The results were very interesting – protein stimulates orexin production. This sort of explains two things – why diets high in protein and fat can actually lead to weight loss and why many people with narcolepsy do better on a high protein diet.

To go one step further the scientists found that amino acids in particular stimulate orexin neurons more than any other nutrient. Previous work by the group found glucose blocks orexin cells so the researchers also looked at interactions between sugar and protein. They found that amino acids stop glucose from blocking orexin cells, in other words, protein reduced the effects of sugar on the cells.

Why is this information important? For the first time it seems possible to ‘tune’ select brain cells to be more or less active by deciding what food to eat. This has proved that not all brain cells are simply turned on by all nutrients, dietary composition is critical.

However, at the moment the problem of getting the big molecules of orexin through the blood brain barrier look very difficult to solve but as it could be worth billions to the drugs companies a way could be found.

A busy 12 months lobbying for change on your behalf

THERE were several areas in 2011 where we felt that the perspective of people with narcolepsy needed to be transmitted to Government departments.

Narcolepsy UK provided feedback to the Department of Work and Pensions (DWP) on the proposed changes to the Disabled Living Allowance (DLA) and the changes planned for ESA. We remain concerned about the proposed changes to the Disabled Living Allowance (DLA) and the changes planned for ESA.

Discussions are taking place with the Minister for Disabled People at The DWP.

Work with the Department of Health has been a little more difficult. For 2012 we want Ann Milton, Public Health Minister, to give a definitive statement of why Pandemrix was offered as a Winter Flu Vaccine when it would have no effect on standard winter influenza.

We are aware of children being given Pandemrix as late as February 2011, months after the warning was raised about the vaccine and narcolepsy.

We are asking the minister, who is responsible for vaccinations, why the UK uses vaccines that have both an adjuvant and thimerosal in them when this practise is banned in other countries. We are also asking that genetic counselling and tests for the HLA subtype DQB1*0602 be offered to families with a history of narcolepsy.
What a year that was – recalls proud chairman

Our 30th Anniversary year was always going to be a busy one and there have been a number of significant developments for Narcolepsy UK during 2011.

BILL HARRIS, chairman of Narcolepsy UK, considers his highlights of the year.

Trustees

We have been delighted to welcome Tom Bamford as a trustee this year. Tom’s area of expertise is websites, and his knowledge is already proving invaluable as we strive to keep our on-line presence up to date.

Support groups

We have spent this year experimenting with different formats for member meetings. On the plus side, we have learnt a lot about what works and what doesn’t work.

However, the numbers of attendees has been much lower than we’d anticipated – and barely a single member attended more than one session. We have more meetings planned for 2012 but if you have any suggestions or would like to get involved then please contact us.

Website

Since its relaunch in September 2010, the website has seen an ever-increasing number of visitors. During 2011, we had over 30,000 unique visitors – making it the most visited narcolepsy website in the world.

The forum has developed into a primary place for people to talk about all aspects of narcolepsy, and we have added plenty of new content – particularly on the benefits side.

We regularly analyse how the website is used in order to help us decide what developments are required, and we now have a trustee in Tom who can help Chris Jones make these a reality.

We have set up a Facebook page and will be Tweeting shortly. We also have plans to add a couple of blogs.

Advocacy

2011 has been a fantastic year on this front, with us helping a dozen sufferers in their fights to get their PCT’s to approve them being prescribed Xyrem.

We have had a near 100 per cent success rate – and the vast majority of the sufferers have experienced significant improvements in their ability to cope with their narcolepsy.

However, we have found that it takes us an average of 50 to 60 hours of John Cherry’s time per case.

His time is limited, and so we will have to limit the number of cases he can deal with in 2012 – or until we secure some funding for advocacy work.

Literature

We issued our first Christmas cards in 2011. While they’re a great start, there is definitely room for improvement. A member has kindly offered to help us on this front – so keep your eye out for new cards later in 2012.

We have also made a start on updating our literature – which takes a surprisingly long time.

We have issued several posters as well as a tri-fold leaflet giving a brief description of narcolepsy.

There are several other documents due for 2012.

Conferences

We held two conferences in 2011 (Sheffield and Cambridge), with almost 300 attendees in total. Sheffield was a great day, with a large number of people able to get direct advice on benefits from a representative from the Citizens Advice Bureau.

For our September conference in Cambridge we had several high-profile speakers, including Professor Emmanuel Minot – who is arguably the world’s leading expert on narcolepsy, and Dr John Shneerson – the UK’s leading expert on narcolepsy.

The weekend also dovetailed with the British Sleep Society’s annual conference, and we were invited to speak at a two-hour narcolepsy session.

Going forward, we plan to have four conferences in 2012 – three regional meets, including one in Scotland, together with one aimed specifically at narcoleptic children and their families.

Benefits helpline

In October we opened a benefits helpline, which is manned from 5-7pm every Tuesday and Thursday evening. Margaret Roxburgh (pictured above) has considerable experience in the benefits system, and she has used this to help lots of sufferers to work through this minefield.

Margaret has always been available to offer support and advice, but the fact that there were fixed hours has meant members know there will be someone at the end of the line. One case which I must mention is Mike. Mike called Margaret in April for advice on Disability Living Allowance, which he had been trying to secure for some time.

Margaret pointed out that he had to apply before he was 65 or he would lose out completely. He was due to reach 65 in just a month’s time, and she helped him through the application process.

In October, he found out he had been successful for full benefits including back-dating to the date he’d applied.

In total in 2011 we have helped members get over £150,000 of benefits they deserve and are entitled to - a great result.
An American’s tale on how to carry on living

Mal Einen, clinical research coordinator at Stanford University Center for Narcolepsy in California, had delegates at the Cambridge conference last year totally absorbed by her talk ‘Living well with Narcolepsy: an American view.’

Committee member Ed Coates gives a summary of her fascinating talk here.

Mal shared how she has learnt to deal with the debilitating effects of suffering from narcolepsy and cataplexy from her early 20s, and now she also offers support and advice to patients of Dr Mignot. She was also one of the first patients to be prescribed and to report on the use of Xyrem.

Mali opened by expressing a strong personal view that it is vital not to let narcolepsy define you as a person but she acknowledged that this was rather easier said than done.

Her journey started as after graduating with high grades in her early 20s, with every prospect of a high flying career in finance. Then narcolepsy and cataplexy intervened, and although she maintained her career for a period it wasn’t without costs and difficulties.

From her subsequent experiences she went on to cover a wide range of practical and psychological aspects of the condition and gave her advice on how to manage it.

Sleep Hygiene

Above all she emphasised the importance of sleep hygiene and routine and explained how beneficial it was to get into a pattern of short sleeps when needed, ideally at similar times each day, however difficult this may seem.

She said the naps should be taken before becoming overtired and explained that she knew when she was becoming grumpy and that was her warning sign – something that struck a chord with several people in the audience.

Holding off against the need for a sleep in her experience resulted in the need later for a much longer.

Without going into detail this is an issue worth further research and indeed will also apply to children and young people in education, where there is a link between performance and the level and type of activity by the individual.

Psychological Penalty

A theme she covered was the contradictions faced and the unbelievable stresses in managing life with narcolepsy, and living with someone with narcolepsy.

With great humour she responded to a question about the ‘psychological penalty’ of being tough. She talked of the costs and stresses, of planning ahead and often masking her needs for sleep.

She talked of the ‘sirens’ going off in her head – ‘don’t take a nap’ when at work for example.

She explained the relief that she feels now since taking Xyrem – mainly that she doesn’t need to make such accommodations either with sleep or with say just having fun.

She also talked about the fact that she didn’t want people to tell her to go take a nap, and helpfully suggested that what had worked for her was to discuss this when not tired and find a code or alternative way of asking her if she wanted one.

Sleep Apnoea

This was just a brief reminder to everyone that people with narcolepsy may be considerably more likely to have some form of Sleep Apnoea as well.

She urged that everyone should discuss this possibility with their doctor/consultant, and she stressed the importance of treating this where necessary.

She also made the point that sleepiness is often a symptom of other things going on, for example Sleep Apnoea, but it can also be affected by a whole range of other things indicating how well someone is – an obvious example being a common cold.

Teeth

All drugs affect the mouth and leave people with dryness. Drink plenty of water was Mali’s top tip!

Advice

The need for people with narcolepsy and cataplexy to get quality and knowledgeable advice was highlighted.

Some in the audience explained their difficulties in accessing this.

Mali stressed the need to keep on asking and if necessary complaining.

She explained her role was often to make contact with patients who had seen Dr Mignot, a while after initial diagnosis. This gave patients and their families time to absorb the diagnosis, find out things about the condition and have more meaningful discussions.

She acknowledged that this sort of service is not readily available in the UK, but reiterated if you don’t ask you don’t get.

Xyrem (Sodium Oxybate)

Mali talked about the massive and life changing effect that Xyrem had had for her and this generated much discussion and interest. There were several members of the audience who were on Xyrem, as well as a larger number who were not.

There was discussion on the process and need for support through the process of getting PCT’s to agree to fund it but Mali, not surprisingly, was unable to help with this discussion.

What she did say, however, is that it is terribly important to ensure that advice is needed about the levels of dose and the way it is taken as there are variations in response.

Committee plans summer family event

THE GENERAL Purpose sub-committee plans to organise a weekend get together this summer for families with children who have narcolepsy.

The intention is to combine sessions on subjects of interest with opportunities to meet and share experiences with other families in a relaxed setting, as well as optional group activities.

The committee would like to hear from everyone who would be interested in participating.

What would you like to see at the event, and is there anything that you can contribute towards making it a success?

To register your interest please send an e-mail to: info@narcolepsy.org.uk with the subject heading saying ‘Family Event.’