



N°10, September 2008

<http://www.neuroprion.com>

The Editorial

By Jens Schell

NeuroPrion is now in its 5th year and we are approaching the end of the official funding of the European Community. So far, I think we can be proud of the achievements of NeuroPrion. Fruitful collaborations cover the whole range of prion research and resulted in many scientific publications. Latest results have been and will be discussed at the annual international conference, Prion2008 in Madrid next week. Furthermore many workshops on specific topics enabled the exchange of new findings and unpublished data. The annual Baden meeting organised by Prof. Herbert Budka is a good example for such a familiar workshop, which has a long tradition in prion research. In 2008 it was coorganized with PrioNet Canada and held for the first time in Montreal. Another important achievement of NeuroPrion is the virtual infrastructure: eDOC, the NeuroPrion intranet, and the NeuroPrion public website. eDOC, widely used today by many of us, offers many tools that simplify the access and exchange of information while assuring the required confidentiality. The latest version of the public website confirms our intention to always do better. Also the strong cooperation with the international CJD Alliance improved the NeuroPrion communication towards the public at large.

But what's next? This questions might be raised by many, especially when realising that the funding of NeuroPrion is running out and prion funding in general is more and more difficult to obtain. The end of the EC-funding will not be the end of NeuroPrion. In such times, good and efficient collaborations will become even more important in order to find answers to the still open questions. An international NeuroPrion association for prion research is presently being created that should ensure the sustainability of the various tools, training and exchange programmes as well as the many collaborations initiated by the Network. The preparations for the NeuroPrion conferences Prion2009 in Greece and Prion2010 in Austria have already started. Like this we will ensure further progress in the interesting and challenging field of prion research and provide information on the existing uncertainties.

Personally, I am looking forward to all the new findings and results, although I will follow them from a distance. After working for 4.5 years as the scientific manager of NeuroPrion, I accepted a position as research coordinator at the Friedrich-Loeffler-Institut in Germany. As I had a wonderful time at the CEA in Paris and within NeuroPrion, this was not an easy decision. However, the possibility to extend my expertise to the animal health and welfare in general was too attractive to refuse. I would like to thank all my direct colleagues at the CEA, who simplified my integration in France, and all NeuroPrion partners for their support of my work. I learned a lot during this time, professionally as well as personally, and French is only one of many aspects. It is always difficult to say good bye, but sometimes it has to be done. May be, in my new function I will be in contact with some of you again, but in any case I will always follow the progress in the field.

Good luck to all of you and thank you all!

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10 years jubilee for Atypical/Nor98 Scrapie

By Sylvie Benestad

Exactly ten years ago, the first case of Nor98 scrapie was diagnosed in a six year old sheep in Norway (Benestad et al. 2003). Nor98 was first assumed to be a rare exotic Norwegian condition until, after the implementation of the surveillance programme by rapid testing, several European countries reported similar cases, calling them Nor98, or Nor98-like, or atypical scrapie, enlarging thereby the horizons of the disease (Buschmann et al 2004; Gavier-Widen et al. 2004, Orge et al. 2004, Onnasch et al. 2004).

After a decade of relatively intensive search what is the situation today? At present more than 1300 atypical/Nor98 scrapie cases are reported through Europe. Cases are also reported outside Europe with one case in the Falkland Island (Epstein et al. 2007), six cases in the USA, one in Canada and one case discovered in a flock originated from New-Zealand strictly kept isolated in the UK. It appears obvious that atypical/Nor98 scrapie is detected wherever the diagnostic conditions are put in place for its detection. This widespread distribution of the atypical/Nor98 scrapie is noticeable especially when considering that in most of the European countries they represent the largest proportion of the total scrapie cases diagnosed.

The peculiar features of atypical/Nor98 scrapie are now well known (reviewed in Benestad et al. 2008). In 2005 the European Food Safety Agency (EFSA) produced a document describing clearly the standard diagnostic differences between the 3 categories of TSE in sheep, namely



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Classical scrapie, Atypical scrapie (including Nor98) and BSE in sheep (EFSA 2005a). Atypical/Nor98 scrapie are characterised by a PrPrSc distribution in the brain prominent in the cerebellar and cerebral cortices, minimal in the brain stem and no detectable PrPSc in the lymphoid tissues (Benestad et al. 2003, Nentwig et al. 2007). Furthermore, the prion protein of these cases shows a special molecular signature recognisable by its characteristic low molecular fragment at around 11kDa (Benestad et al. 2003; Arsac et al. 2007). Atypical/Nor98 affects older sheep (Fediaevski et al 2008) and does not follow the rules established by Classical scrapie regarding susceptibility/resistance of the PrP genotypes, targeting particularly the AHQ and AF₁₄₁RQ alleles, and in a lesser extend the ARR allele (Moum et al. 2005; Lühken et al 2007).

An evaluation of the rapid tests has been organised by the EFSA in 2005 (EFSA 2005b). For atypical/Nor98 scrapie, the results showed that only three out of nine (IDEXX Herdcheck, Bio-Rad TeSeE and Bio-Rad TeSeE Sheep/Goat) were recommended for efficiently detecting PrPSc in the brain stem, an area showing minimal amount of PrPSc in most of the atypical/Nor98 scrapie cases. Despite these recommendations, a certain proportion of tests in small ruminants is still performed world wide using a screening test with low sensitivity for detection of atypical/Nor98 scrapie, suggesting that its presence could still be under evaluated.

Atypical/Nor98 scrapie is diagnosed most of the time by testing apparently healthy sheep, or in sheep showing clinical signs that are not necessarily indicative of scrapie, mostly loss of body condition, abnormal behaviour and ataxia (Benestad and Bratberg 2007). In addition, the atypical/Nor98 agent is less resistant to proteinase K (Simon et al 2008) and is not recognised by some diagnostic tests (Buschmann et al 2004). This feature and the fact that the agent is so peculiar brought doubts in its transmissibility ability until the publication of successful intracerebral transmission into ovine transgenic mice (Le Dur et al 2005) and into sheep (Simmons et al. 2007). Atypical/Nor98 scrapie was then accepted as a truly infectious agent that kept its features upon experimental transmission.

The NeuroPrion task group on epidemiology recently published data allowing a good comparison between the epidemiological situation of atypical/Nor98 and Classical scrapie from 20 different European countries (Fediaevski et al. 2008). The major conclusion is that the prevalence estimates of Classical scrapie has more variation both geographically and chronologically than those of the atypical/Nor98 which is remarkably homogenous. In contrast to Classical scrapie, few reports of multiple cases have been described in atypical/Nor98 flocks and a case-control study found that movement of animals was not a risk factor for the transmission of atypical/Nor98 between flocks (Hopp et al. 2006). All these observations indicate that if atypical/Nor98 is transmissible from sheep to sheep the contagiousness rate is very low. All taken together, it is now not possible to exclude the possibility that the two types of scrapie could have a different aetiology and even if the frequency of the atypical/Nor98 is apparently higher than it is for the sporadic form of the human Creutzfeldt-Jakob disease, a spontaneous origin could be speculated.

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The Baden 2008 meeting

held in Montreal, Canada on June 13-15, 2008

Exceptionally this year, the Baden meeting (normally held in Baden, Austria after which it takes its name) was held in Montreal, Canada. This was made possible due to the NeuroPrion and PrioNet Canada collaborations which are strengthening more and more. The meeting was again a great success. NeuroPrion has filmed all the presentations of the conference (~20) and they are now accessible via the private website of NeuroPrion (eDOC). These are open to all Baden2008 participants and NeuroPrion members. For more information contact Steve Simoneau (steve.simoneau@cea.fr).

Below, two commentaries about the meeting. The first by one of the speakers, Valerie Sim, and the other by a student who attended the meeting, Danielle Padilla de Beer.

Summary of the meeting by Valerie Sim



With beautiful Montreal, Quebec, as a backdrop, researchers from across Europe and North America recently met to discuss new developments in the prion world. Session I covered some basic aspects of the field.

The role of the N terminus of PrP was mentioned by several speakers. Nigel Hooper (University of Leeds) discussed the inverse relationship between PrP expression and the β -secretase cleavage of amyloid precursor protein, an effect dependent on four N terminal residues of PrP. Amino acids 32-93, including copper-binding octarepeats, are required for the observed protective effect of PrP on the size of brain infarction (Hans Kretzschmar, University of Munich). A smaller portion of the N terminus, amino acids 30-49, appears to be responsible for the induction of mRNA aggresome formation in cell models expressing cytoplasmic PrP (Xavier Roucou, University of Sherbrooke). The similarity of these aggresomes to the chromatid bodies produced during spermatogenesis is striking, and generates questions about a role for cytoplasmic PrP in translational regulation and cell death.

Turning to the abnormal form of PrP, Ilia Baskakov (University of Maryland) presented atomic force micrographs of recombinant PrP fibrils whose morphology depended on their creation by shaking or rotation. Once formed, these fibrils could template their specific structure onto fresh recombinant PrP irrespective of ongoing shaking or rotation. Such studies may help elucidate the fundamental principles behind prion strain variation.

The session then moved on to electron and atomic force micrographs of fibrils isolated from infected mice that express PrP without its glycosylphosphatidylinositol anchor (Valerie Sim, Rocky Mountain Lab, NIH). Differences in protofilament widths and periodicity tendencies were observed among three strains: 22L, RML, and ME7, suggesting that fundamental differences in protofilament cores may underlie some features of strains.

Just as these anchorless mice, when infected, develop huge plaques with little if any clinical phenotype, there is a discordance between plaque number and spongiosis in Gerstmann-Sträussler-Scheinker disease (Pedro Piccardo, Food and Drug Administration). Heavy plaque burdens can occur without spongiosis, and spongiosis can develop without PrP amyloid. These observations highlight the possible importance of smaller oligomeric species in prion disease pathogenesis. Ways to further characterize these oligomers by field flow fractionation and light scattering were discussed (Valerie Sim, Rocky Mountain Lab, NIH).

Recent advances in diagnosis included a new version of amplification detection which substitutes recombinant PrP for brain homogenate, and shaking for sonication (Valerie Sim, Rocky Mountain Lab, NIH). This Quaking-Induced Conversion ("QuIC") discriminates infected from uninfected hamsters using 2uL of cerebrospinal fluid, has a sensitivity of 100ag (less than one lethal dose) in a 46-hour reaction, and can be performed in a single 4-hour reaction with a sensitivity of 100fg.

Another diagnostic approach was reviewed by Neil Cashman (PrioNet Canada) who described epitope protection technologies. Ruth Gabizon (Hadassah University Hospital) presented evidence for a specific covalent signature of abnormal PrP due to the oxidation of methionine residues, which may provide a new target for detection and therapeutics.

The Baden meeting provided network opportunities for both new and well-established researchers. There was much talk of collaborations across nations, and across oceans, with hope for a stronger relationship between NeuroPrion and PrioNet Canada in the years to come.

Summary of the meeting by Danielle Padilla de Beer



From June 13th to 15th 2008 I have had the opportunity to attend the 12th annual Baden Meeting organized by PrioNet Canada and NeuroPrion in Montreal.

It is unusual that a PhD student attends this kind of meetings, but for different reasons I have been there, representing my laboratory.

It has been a great experience. I had the possibility to know the latest advances in the prion field, presented by the different prion experts, and I have also obtained a more critical point of view of the current prion science.

In my opinion the different lectures were very well selected, since they represent the different topics of prion diseases. It was also a great opportunity to learn more about presentation skills. On the other hand, it was a great opportunity to know more about the PrioNet Canada network and it was very interesting to hear about possible future collaborations between Europe and Canada, including the promotion of student exchange. It was for me a pleasant surprise to hear the importance given by both neuroprion and PrioNet Canada to the involvement of students in activities, oriented to our formation, like the continuation of the NeuroPrion Student workshop, organized this year in Bratislava, and the possibility of future supports for student exchanges between the different research groups.

Actually, I'm not able to compare this meeting with others realized on previous years, because it was my first, but if I compare it with the international Prion conference organized each year by NeuroPrion, the Baden Meeting was more "familiar". This carries to a better way to meet the different prion experts and to make new contacts. These interactions are more difficult at the annual Prion Conference, probably because there were much more people. Other important aspect present at the Baden Meeting was the existence of extended critical discussions after each speech, a very interesting fact that doesn't happen a lot at the annual Prion Conference.

I have also enjoyed a lot the Scientific Walk in Old Montreal which was a good moment to meet the different persons assisting in a more relaxed environment.

In summary, it has been a very great and completely new experience for me that I have enjoyed a lot. Finally I would like to thank NeuroPrion and PrioNet Canada for providing me the possibility to assist to this meeting and congratulate them for the excellent organization of the event.

NeuroPrion Student Summer School 2008

6th-9th August, Bratislava, Slovakia

The NeuroPrion network recently held a summer school in Bratislava aimed at PhD students who want to develop their communication and presentation skills. This course was an opportunity to develop skills essential for presenting science. Furthermore, it provided a chance to meet PhD students and established researchers investigating prion diseases throughout Europe. The four day course was a combination of lectures from invited speakers and interactive workshops, with an opportunity for students to present their research on the final day.

The workshops were led by Dr. Christian Dumpitak, an established scientist and keen thespian, and Knut Hannerman, a historian and philosopher who provided a useful "non-science" perspective to the students. They provided an engaging series of tasks aimed at developing specific aspects of communicating science, including controlling nervousness, building an argument and the use of media, to name but a few. All tasks were highly interactive and allowed the students to practise the theory behind each session. They encouraged a friendly and informal setting which allowed the students to feel comfortable participating in activities and to use feedback to improve performance and increase confidence. On the final day, the students gave a 15 minute presentation of their research followed by questions from students and invited scientists. This allowed the student to present their work to an international audience and make use of skills learned during the workshop.

In addition to the workshops, lectures were given about the pharmaceutical industry and the difficulties in developing risk assessments for prion diseases. These lectures gave an interesting perspective to students considering other areas of research out with academia. The course was well organised by Jens Schell and social events were provided by our Slovakian host Tibor Hianik where local cultural excursions were enjoyed. Special thanks to Igor Grman, a student of Prof. Hianik, who took time to show us around the city and allowed us to fully enjoy the exceptional venue.

In general, the course was enjoyed by all students and provided valuable lessons essential for anyone starting out in scientific research. We would very much recommend this course to any PhD student wishing to hone their communication skills as the workshop helped to build confidence and develop key skills necessary for future academic success.

Laura McCulloch
Neuropathogenesis Division,
Roslin Institute, University of Edinburgh

Getting to know the The CJD International Support Alliance (CJDISA) better!

2nd part (1st part in the N°9 May 2008 issue)

The CJD International Support Alliance (CJDISA) was formed by a group of grassroots nonprofit organizations that share one vital factor: a commitment to prion disease victims, their families, and those at risk for prion disease. CJDISA was founded to fill the gap that exists on an international level and to assure excellence in the service to individuals affected/at risk of prion disease, their families, and caregivers. The participating organizations are dedicated to work together in meeting the educational, social, emotional, spiritual and practical needs of those they represent. Under the CJDISA umbrella, these organizations collaborate on educational initiatives, information dissemination, resource allocation, program design and implementation, and advocacy.



In this issue of the NeuroPrion Newsletter, the following organizations will be introduced.

- CJD Alliance (UK)
- CJD Support Network (UK)
- Associazione Italiana Encefalopatie da Prioni ONLUS (AIEnP ONLUS)
- CJD Support Network (Japan)

CJD Alliance (UK)

CJD ALLIANCE was formed in August 2005 and is based in the UK. We are an independently run organisation involved in TSE's (Transmissible Spongiform Encephalopathies) such as Creutzfeldt-Jakob Disease (CJD).

Our primary functions include:

- To disseminate information on research to enhanced early diagnostic tools
- To disseminate information on research into putative treatments
- Collating and publishing relevant information
- Providing invaluable information to families affected by CJD

Through our extensive global database of researchers (> 1000), CJD Alliance is actively involved in a number of key activities and aim to use our combined knowledge to the benefit of patients and their families. The Alliance firmly believes that through our independence and past, current (and future achievements) leading to our formation, further progress can be made in the search for enhanced diagnostics, effective therapies and ultimately, treatments.

We are currently in the process of re-building this website www.cjdalliance.net and this will continue to grow in content over the coming months.

Co-Founders, Mr Don Simms and Mr Graham Steel can be contacted via email info@cjdalliance.net

CJD Support Network (UK)



The UK CJD Support Network is a patient support charity which was established in 1994 and is now recognised as the leading UK charity for all forms of CJD.

The charity has one full time employee, the National CJD Co-ordinator and has a volunteer management committee who have had family experience of all strains of CJD. The Chairman, Dr Angus Kennedy, is a consultant neurologist who has had considerable experience of CJD cases and has worked for the National Prion Unit with Prof. John Collinge.

Through the 24 hour helpline we provide practical and emotional support to patients, families and professionals affected by or living with a heightened risk of CJD through blood and surgical instruments. We receive approximately 1000 calls per year of which 40% are from a relative of a person who has been given a diagnosis of CJD.

The CJD Support Network publishes accurate and up to-date information, written by experts, on sporadic, vCJD, Genetic and Iatrogenic CJD and issues surrounding CJD. Although the information is developed and written for families, the information is widely used and distributed by professionals in the field.

Information about CJD and the issues surrounding the disease can be viewed and downloaded from our website at www.cjdsupport.net. Audio information is also available.

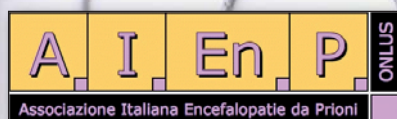
Through the 24 hour helpline our aims are:

- To offer support to individuals and families concerned with all forms of CJD.
- To offer support to people who have been told they are at a heightened risk of CJD through blood and surgical instruments
- To provide emotional support for carers and to link families with similar experiences of all forms of CJD..
- To offer financial support for families in need.
- To provide accurate, unbiased and up to-date information and advice about all forms of CJD to patients, families and professionals.
- To provide a national helpline on all forms of CJD.
- To promote good quality care for people with all forms of CJD.
- To promote research into all forms of CJD and the dissemination of research findings.
- To network closely with other voluntary and statutory services for CJD
- To develop a public response for all forms of CJD

We have representation on all Department of Health specialist committees in the field of CJD and we ensure that patients and families needs and wants are at the centre of all policymaking.

We work closely with international groups both independently and through the International CJD Support Alliance to maximise co-operation and co-ordination of information and activities.

Gillian Turner
National CJD Co-ordinator
UK CJD Support Network
Website : www.cjdsupport.net



Associazione Italiana Encefalopatie da Prioni – ONLUS

Following the attendance of the workshop held at the Prion2006 meeting in Torino (organised by NeuroPrion), Italy, for relatives of CJD patients, a small group of family members promoted the foundation of an Italian CJD support network, thanks to the help of Prof. Maurizio POCCHIARI (Istituto Superiore di Sanità – I.S.S. – Roma), Dr. Fabrizio TAGLIAVINI (Carlo Besta Neurological Institute – Milano) and Dr. Gianluigi FLORONI (Mario Negri Pharmacological Research Institute – Milano).

Each founder of the Association had lost a loved one to this devastating disease and recognised the need to represent the problems facing CJD families to the institutions in charge of prion disease.

From December 2006 to June 2007 the group met at the Istituto Superiore di Sanità (ISS) in Rome to format the aims and objectives of the Association, that became officially known as the Associazione Italiana Encefalopatie da Prioni – ONLUS (A.I.En.P.) in June 2007.

The mission of A.I.En.P. is to promote and help the scientific research and to support families touched by Prion Encephalopathies in particular CJD and GSS.

The Prion Encephalopathies Italian Association was formally established in September 2007 by a public Notary; the structure of the Association, a non-profit making association, with sixteen co-founder members, is the following:

- Mr. Roberto BORGIS, President;
- Mrs. Raffaella ROBELLO, Vice President;
- Mrs. Malvina GALOFARO, Treasurer and Secretary.
-

The Governing Board consists of the President, the Vice President, the Treasurer, and the two members Mrs. Angela CHILLE' and Mr. Marco TERRACINA.

At the PRION 2007 meeting in Edinburgh (September 2007) the A.I.En.P. was represented by President Mr. Roberto BORGIS, Mrs. Angela CHILLE' and Mr. Federico SCHIAVO (founding members). During this international event Mrs. Suzanne SOLVYNS, President of the CJDISA and Mrs. Florence KRANITZ, President of the CJD Foundation, introduced the newly founded Italian support network as a new member of the CJD International Support Alliance.

In October 2007, A.I.En.P. attended the 38th Meeting of the Italian Society of Neurology held in Firenze, Italy and in December 2007 instituted a bank account and a mail account in order to receive donations and collect funds to promote its objectives.

In February 2008 the A.I.En.P. web site was on line at the following address: www.aienp.it; English, French and Spanish versions are available as well.

On 17th and 18th May 2008 A.I.En.P. was represented by its President at the National Conference of the CJD Support Group Network in Melbourne, Australia; Mr. Roberto BORGIS and Mrs. Raffaella ROBELLO will attend the CJD Foundation Family Conference in Washington DC on 10th-13th July as well as the NeuroPrion 2008 meeting, which will be held in October, 2008 in Madrid.

All co-founding members of the A.I.En.P. are volunteers and, by the end of May 2008 membership numbers had reached sixty. With awareness we expect to increase our membership to one hundred before the end of this year.

Since the beginning of this year the main activity of the Association has been to raise funds in order to finance two different research projects and plans to produce information materials by the second half of this year A.I.En.P. intends to contact Neurology Departments of Italian Medical Centres.

Appropriate contacts have been set up with the Italian Ministry of Health, through the I.S.S., in order to obtain the acknowledgement of Prion Encephalopathies as rare diseases.

Website : www.aienp.it

www.neuropriion.org

The new NeuroPrion public website now available

This website aims to :

- Explain what prions are to the general public
- Present the NeuroPrion Network and its resources
- Facilitate the partnerships with industrials and other research institutes

Getting to know the The CJD International Support Alliance (CJDISA) better!

Continued...



CJD Support Network (Japan)

In Japan, 132 people were infected with CJD due to transplant of prion contaminated human dura mater imported from Germany. This resulted in legal actions against the Japanese government and pharmaceutical companies called «Yakugai CJD suits».

Every year, 2 or 3 new patients are detected, and this is expected to continue until about 2015 at least.

After the reconciliation of the Yakugai CJD suits in March 2002, the CJD Support Network of Japan was established in June that year. Our support network consists of victim families, volunteers, medical workers, researchers, lawyers and other professionals. Our mission is to support the families affected by any form of CJD. It is social and mental support. We provide «peer support» to help bereaved families and current caregivers which is the best way to understand them.

Contact: cs-net@takenet.or.jp

Website: <http://www.cjd-net.jp>

Submitting to the NeuroPrion Newsletter:

You are a NeuroPrion member or not? You can advertise in the Newsletter about training opportunities and job offers or others subjects which might be of interest to the scientists of the Network. To do so, simply send us your request by mail to the following address: neuropriion.newsletter@igh.cnrs.fr.

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Farewell Jens Schell!

After 4½ years of being the Scientific manager of NeuroPrion, Jens is heading for new challenges by joining the Friedrich-Loeffler-Institut as a research coordinator. I am confident that during his NeuroPrion experience, Jens learnt a lot, answering several times a day to questions that he did not have the answer, chasing all over the virtual and real world scientists, partners, administrative officials for reports, forms etc.. He probably had a lot of “fun” combining and homogenizing information from the 52 NeuroPrion partners and being sure that our hundreds of milestones and deliverables were on time, reached or completed. If he can thank us for this great experience (we did sometimes our best to complicate his work and therefore improved his training ;-)), we can also thank him for listening calmly to our queries and sometime complaints, for being very professional and for trying to find the best solution for us.

So I would like in the name of all of us, wish the best for him in his new professional life. I know that he will always remember his NeuroPrion experience in Paris that is notably marked by the fact that he has now in the morning, in addition to German bradwurst, French Parisian croissant for breakfast ;-)

Sylvain Lehmann
Editorial committee

Announcements

Prion conferences:

- *The New Prion Biology: Basic Science, Diagnosis and Therapy*, Venice, Italy, April 2-4, 2009
website : http://www.istitutoveneto.it/prion_09/

Other events:

- Gala Fundraising Dinner, Australian CJD Support Group Network November 14th, 2008
website : <http://cjdevents.org/>

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