

A.I.En.P. Associazione Italiana Encefalopatie da Prioni

The Italian Association for Prion
Encephalopathies – A.I.En.P.

Family Meeting

Goettingen, March 3, 2012

Speaker: R. Borgis

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- Prion encephalopathies

Epidemiological data

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Since 1993 a National Register for Prion diseases is active at Istituto Superiore di Sanità in Rome, Italy.

The system of surveillance on human encephalopathies was created in response to the spread of the epidemic of bovine spongiform encephalopathy that struck Britain at the beginning of the 90s.

The National Register ensures a single epidemiological analysis for a rare disease and keep monitoring the evolution of the sporadic and familial forms and any possible case of Bse.

In Italy the majority of cases, about 85 percent, relate to the sporadic form, while the familial forms stand at 15 percent.

Source: ISS web site

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Numero di decessi in Italia (aggiornata al 30 giugno 2011)								
Anno	Segnalazioni	MCJ Sporadica	MCJ Iatrogena	MCJ Genetica	GSS [°]	FFI ^{°°}	MCJ Variante	Totale
1993	51	27	0	6	1	2	0	36
1994	62	33	0	6	0	1	0	40
1995	52	28	0	6	1	1	0	36
1996	77	51	0	7	0	1	0	59
1997	139	47	1	12	0	1	0	61
1998	143	64	2	9	0	1	0	76
1999	192	74	0	17	0	0	0	91
2000	177	60	0	23	4	3	0	90
2001	219	86	0	13	1	0	0	100
2002	201	77	0	11	3	0	0	91
2003	192	79	0	8	1	1	1	90
2004	176	78	0	20	0	0	0	98
2005	236	108	1	20	2	0	0	131
2006	238	96	1	31	5	2	0	135
2007	208	96	1	18	1	0	0	116
2008	217	92	0	12	0	0	0	104
2009	191	105	0	8	1	0	0	114
2010	216	93	1	10	6	0	0	110
2011	116	31	0	3	0	0	1	35

[°]GSS, sindrome di Gerstmann-Sträussler-Scheinker

^{°°}FFI, Insonnia fatale familiare

Source: ISS web site
Updated June 30,2011

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- A brief history of A.I.En.P.

A.I.En.P.

Associazione Italiana Encefalopatie da Prioni

- A.I.En.P. – the Italian Association on Prion Encephalopathies is a no-profit making association formally established in September 21, 2007 by 16 founding members from North, Center and South of Italy; all are relatives (sons, daughters, husbands and wives) of beloved ones stroke by prion encephalopathies, in particular sporadic CJD and GSS;
- The headquarter is in Rome;
- From 16 founding members A.I.En.P. reached 103 members.

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- The main activities in 2011

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- **Contact with families**

During 2011 A.I.En.P. was brought into direct contact with families affected by prion diseases with an average of **3 phone calls per week**.

A.I.En.P. for each case and family gives both moral and concrete help, especially when “difficult” conditions are described deriving from uncorrect behaviour both by health professionals and hospitals.

- **Recognition as rare disease**

In March 2010 A.I.En.P. formally asked the Ministry of Health for the recognition of prion diseases as rare diseases (which means economic relief for the families). The Ministry formally answered that our request is in stand by because the Ministry of Finance has to give a technical advice. It also underlined that only familial forms will be taken into consideration at this moment. We are currently waiting for an answer.

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- **Communication**

At the beginning of 2011 a renewed A.I.En.P. institutional web site is on line.



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- **Fund raising activities**

A.I.En.P. fund raising activities are active through:

- **members' annual fees**

- **donations by privates (individuals, corporate, institutions)**

- **5 per mille:** in 2010 A.I.En.P. received the amount of 2008 (9,671.43 eur – 233 choices) and in 2011 received the amount for 2009 (9,136,65 eur – 211 choices)

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2nd Italian Family Day dedicated to prion diseases

Mario Negri Pharmacological Research Institute

Milan, December 4, 2010

A.I.En.P organised its second Italian meeting specifically dedicated to prion diseases. The meeting had scientific lectures in the morning and a round table in the afternoon in order to share experiences, ideas, best practice, etc.

The speakers were the most important scientific experts on prion diseases and come from Italy, USA, UK and Germany.

45 families attended the event.

Simultaneous translation was provided to all the attendees and speakers.

The participation was free of charge.

The video of the 2nd Italian Family Day dedicated to prion diseases can be downloaded on A.I.En.P. web site www.aienp.it

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In 2010 the Board of A.I.En.P. decided to give a **grant of 15,000 .00 Eur** to the Neuropathology Unit of the Neurological Institute Carlo Besta, Milan, coordinated by Fabrizio Tagliavini, **to support a researcher for the research activities on prion encephalopathies.**

The grant was focused on two innovative therapies on prion diseases coordinated by Dr. Fabrizio Moda. One work was published on *Nanoscale* and the other one received an honourable mention at the Student and post-doctoral fellow poster competition award at Prion 2011.

In 2011 the Board of A.I.En.P. decided for a new grant of 18,000.00 Euro to the Neuropathology Unit of the Neurological Institute Carlo Besta for the trial on doxycycline



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_ The therapeutic value of writing



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In 2010-2011 A.I.En.P had the privilege to witness the importance of writing in overcoming the pain of losing a loved one because of these terrible diseases.

2 of our members and a supporter wrote and published a book and a university thesis work.

Evalda Capirchio: *The destiny of being rare – The voyage of Sergio Chillé* - 2010

Memories of Sergio Chillé written by his wife (and founding member of A.I.En.P.).

Raffaele Pallavicino: *To you, who are part of me*, 2011

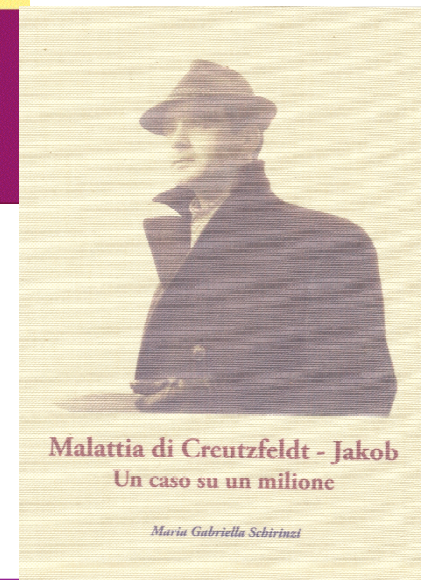
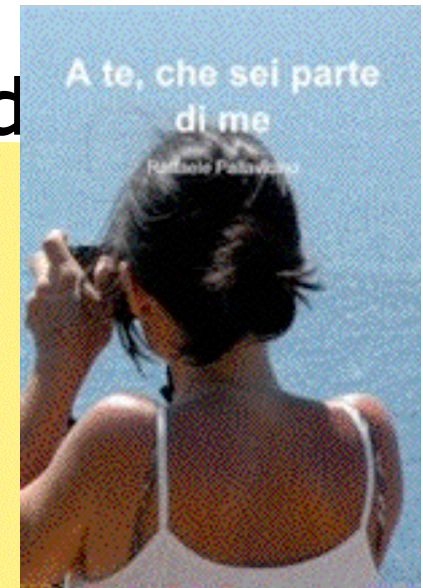
The story of Valeria, a special friend and a special friendship.

Maria Gabriella Schirinzi: *CJD – One in a million*, 2008-2009. Thesis work for her University degree in Educational Sciences, Salento University



IL DESTINO DELL'ESSERE RARI
Il viaggio di Sergio Chillé

 EDIZIONI NEMAPHYS



Malattia di Creutzfeldt - Jakob
Un caso su un milione

Maria Gabriella Schirinzi

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Maria Gabriella Schirinzi – CJD – One in a million.

MG in her University thesis work wrote the story of her father, Antonio Luigi Schirinzi, affected by sCJD and how the writing helped her in overcome the pain. This is her thought about the therapeutic value of writing to overcome the pain

Caring for a person is a real opportunity to increase our personal sense of life.

The disease can become a resource for both the sick person and for those around him, giving new meaning and value to life as a whole.

We can learn from our experience as caregivers that when life changes its color we have to look at it with different eyes, because there is a force within us that makes us absorb even the hardest shots and therefore change the way we see things and makes us go back to life.

*To make sense of pain means to find elements of light and transform it into a place of growth. A wound that opens to light gradually can be healed and cured.
To overcome the pain we must open our hearts and minds.*

To open up to others requires humility and courage, but then produces inner freedom, balance, opportunities to love and be loved.

*The **writing**, the autobiography of grief, the story telling is therapeutic and liberating and allows a relaboration of the trauma and mourning itself.*



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Everything we **write** about us becomes our identity card. To decide to **write** your own story is a marker to start again our life's journey, to overcome the difficulties and the research for new destinations. **Writing** on ourselves is a hard work that gives you back energy and joie de vivre.

Writing is like a drug; when you live there is always something to medicate. **Writing** conceived as art of remembering can be a therapy or even a cure. **Writing** gives consistence to memories.

Writing is a self-healing method. It gives dignity, a history, a remembrance to those for whom it is said and written.

Writing is a gesture of gratitude, of compensation, of symbolic restitution, to those who are not longer with us but left us a strong, beautiful and permanent memory in our lives.

Those whom we remember in our **written** memories become immortal.

To witness through **writing** our own experiences is a moment of collective participation and of renewal of memories of the loved ones who are no longer with us to the new generations.

MariaGabriella Schirinzi



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Thank
You

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