

**Berlin Research Symposium**  
**April 2008**  
**Summary Report by Karen Johnson**

The Berlin Research Symposium was a one day event held on April 11, 2008 in Magdeburg, Germany and entitled "Hereditary Neurodegeneration - Mechanisms, Genes and Phenotypes". This was an event of the Tom Wahlig-Foundation: "To put researchers in touch with each other..... and to do everything possible to find a cure for the illness in the long term." The symposium was scheduled to coincide with the three day German Neurological Congress which was also held in Magdeburg.

There were about 60 participants, mostly researchers from Germany, USA, Italy, Ireland Scotland and Denmark. Patient representatives came from places including Germany, USA, Norway, Spain and the UK.

Here are some highlights:

- \* Researchers openly shared information including a Q&A session after each presentation, and at the end of the day said it was very much worth attending. As an example, in one instance researchers were discussing and sharing techniques for carrying out a particular process and spoke of visiting each other's labs to learn from each other.
- \* The SPF's Scientific Advisory Board member Dr. Evan Reid from Cambridge was there. His presentation was titled "Functions of spartin, the Troyer syndrome protein".
- \* Dr. Tobias Lindig of Stuttgart, well known for his research on thinning of the spinal cord and corpus callosum with HSP, was attending the 3 day conference and dropped in to chat.
- \* Dr. Rebecca Schule at Tübingen, Germany is working on a Gene Chip that will test for 15 different HSP types and is expected to be available this summer.
- \* Dr. Elena Rugarli of the University of Milan, widely considered to be one of the leading HSP researchers in the world, made a presentation entitled "Mechanics of axonal degeneration in HSP". She discussed her research with SPG7 mice and how she was able to correct their condition.
- \* Dr. S Zuchner of the University of Miami and an SPF grant recipient did not attend. His scheduled talk was "The genotypic and phenotypic spectrum of SPG31 - implications for molecular studies". Dr. C Neusch of the University of Göttingen, Germany was also on the program but did not attend.
- \* A woman HSPer from Norway uses an adult sized (stand on top, unmotorized) foldable kick scooter. She walks badly without it but with it is quick and cool and yes - even graceful! She has been using it for years and believes that she has

learned/improved her balance with it and gets around very quickly. Also nice, this equipment is cheap and easily transportable.

\* A researcher from California, Dr. William Saxton concluded his presentation titled "Kinesin-1, Kinesin-3, and fast transport of axonal organelles in Drosophila motor neurons" with something he said he'd just learned. He acknowledged the difference between patients' focus and desire for a cure and the main focus of research being on the understanding of the disease on the genetic level.

\* The German HSP patient group is testing an electronic device (3 month test period) from King Fisher Healthcare of Belgium ([www.kfhealth.com](http://www.kfhealth.com)). Tests should conclude mid-June.

\* Reminder: PTC-124 is in Stage 2 trials, being administered to patients in a clinical setting.

\* Rudi Kleinsorge, President of the German HSP support group, is very excited about a 'zinc finger' technology from Sangamo ([www.sangamo.com](http://www.sangamo.com)), a California based company. From their website it is described as "technology in development of ZFP nucleases to correct DNA sequence of a gene containing a disease-related mutation or disrupt the sequence of a gene that facilitates disease". Rudi talked with each of the presenting researchers about this and they were all interested and wanted more information about it.

\* The German HSP group now is the equivalent of a tax free nonprofit organization and they are turning attention toward fund raising.

\* There is difficulty finding E. European and Russian HSPers to bring them into our worldwide patient community. Translations of medical terminology can make finding HSP information and/or support groups through web searches very difficult.