

2008

1998 – 2008: 10 years Tom Wahlig Foundation

General



In its jubilee year 2008, the Tom Wahlig Foundation continued to be active in a number of fields. The focus in the past few months has been particularly on publicity work in order to attain a higher media profile for the foundation and its goals.

As in previous years, the central focus of the foundation's day-to-day work was the support of HSP research. For example, we held our annual international symposium in Magdeburg at which we welcomed HSP researchers from across the globe. We were also present at a number of large scientific congresses and we started a new research project in Jena.

Publicity Work

The year's activities focused particularly on the development and professionalization of our publicity work. We aim to attract more attention to rare diseases such as HSP while promoting our own foundation in the process. With this in mind, we have appointed a journalist, Simone Kötter, who joined our team a few months ago. She is the contact person for press enquiries and co-ordinates our foundation's publicity work.

As a first step in this direction, we launched the "pacesetters" initiative in summer 2008. This campaign aims to encourage celebrities to take a small symbolic step for people with HSP who, themselves, are no longer able to walk. It entails a public statement made by the celebrities about the work of our foundation, which we can, for example, use for promotion purposes on our website. This celebrity endorsement results in our being "celebrated" far more in the public eye.

Within the space of a few months, we have been able to convince several celebrities to join in our campaign. We have, so far, been able to publish seven pacesetter statements including that of the internationally acclaimed conductor, Bruno Weil, the long-standing president of the German Research Society (DFG), Professor Ernst-Ludwig Winnacker, as well as the honorary captain of the German national football team, Uwe Seeler. Further development of this campaign in 2009 is currently under discussion.

There was great media coverage of TWS-related activities last year. In a joint circulation of 900,000 copies, the Chemists' magazines "Linda", "TV Gesund" and "Leben" as well as "das Magazin aus Ihrer

Apotheke" printed a double-page report on Henry Wahlig's fate and his connection to the TWS pacesetter, Uwe Seeler. Against the backdrop of a charity football match in aid of the TWS, many newspaper articles were published about our foundation. The radio station "Antenne Münster" also presented Henry Wahlig and the TWS in their own broadcast. Towards the end of the year, the renowned news agency "ddp" broadcast an announcement concerning the creation of HSP consultative surgeries in Saxony and Thuringia.

Symposia and Congresses

In pursuing our publicity work, we have not, of course, lost sight of our main priority: concern for sufferers and promotion of scientific research in the HSP area. At the beginning of April, the 8th TWS research symposium took place as part of the DGKN congress in Magdeburg. 52 participants from 9 different countries set a new record of international diversity and bore witness to our foundation's success in creating a constantly growing research family for HSP. The "get-together dinner" financed by Dr. Tom Wahlig, in which HSP researchers from across the globe gathered around one table, testified to exactly how close the co-operation within our area of research has meanwhile become.

In September 2008, the TWS was represented once again at the annual DGN (German Neurological Society) convention. Neurologists and other interested parties were able to find out about the disease pattern of HSP and to become familiar with the work of our foundation. We would like to take this opportunity to thank Mrs Christel Meier, our foundation's "angel", whose unselfish dedication in representing the TWS on such occasions is greatly appreciated.

Promotion of projects

The direct promotion of projects is also an area which was not neglected in 2008 even if we did only authorize the financing of one new project during the year. A total of five universities in two different countries started working together on an analysis co-ordinated by Dr. Christian Beetz, from FSU in Jena which aims at a genetic classification of a new form of complicated spastic paraplegia.

The reason for the slightly reduced level of project promotion by TWS is a change in the promotion policy of our foundation. We will be making further announcements in this connection during the course of 2009.

HSP Consultative Surgeries

One important TWS success is the establishment of a network of HSP consultative surgeries throughout Germany where those affected can be sure of receiving professional and comprehensive care and advice. Previously there was a large gap in this network in the east of Germany. The TWS

was, thus, pleased to set up three new consultative surgeries in Dresden, Chemnitz and Altenburg. Dr. Tom Wahlig visited all the clinics involved personally and left assured that HSP patients were receiving appropriate care and advice there. A further location had already been established at the University of Münster in January 2008.

The TWS will be continuing to extend and update this network in 2009.

Donations

In May 2008, the financial services firm AS Finanz located in Münster held a charity football match in aid of our foundation. Representatives of AS Finanz, along with players from "Münster Mammut" and around 400 visitors listened to Henry Wahlig's address concerning the aims of our foundation and made donations to the good cause. The total sum of €2600 was handed over to Dr. Tom Wahlig at a ceremony held at the Cineplex Cinema in Münster on 4th December.

In spring 2008, the firm Kieser Training sold a book containing feedbacks from previous participants. €2 from every book sold went to the TWS, which resulted in a sum of €2000 euros being transferred to our foundation's account in July 2008.

Our foundation's mascot, "Tommy-bears", also enjoyed great popularity in 2008. Following a competition, won by Mrs Melanie Fischer, in which names were proposed for the bears, they were christened Harry, Susi and Pauli. The Tommy-bears can be purchased here on our website. Proceeds go to the TWS.

Private and corporate donations to the TWS amounted to a total of €55 000 in 2008 (up to 20.12.08). We would like to extend our appreciation and gratitude to all our donors.

In the coming year, the TWS intends to continue moving in the same direction and to intensify its publicity work. In particular, our project promotion will assume a higher profile so that an even greater number of young researchers are encouraged to take up HSP-related projects.

In 2009 the TWS will continue to support the co-ordination of HSP research endeavours as its main focal point.