

## **The History of the Jaeb Center for Health Research**

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*Founder of the Jaeb Center for Health Research*

I started the Jaeb Center for Health Research (JCHR) in 1993. My story prior to that is that I was trained as an ophthalmologist and joined the faculty of the University of Michigan as Director of the Neuro-ophthalmology Service in 1982, subsequently moving to a similar position at the University of South Florida (USF) in 1986. Starting in 1985, as Chairman of the multi-center Optic Neuritis Treatment Trial (ONTT) funded by the National Eye Institute (NEI), I had the good fortune to have our Coordinating Center at the Biostatistics Center at George Washington University under the direction of Paddy Cleary and John Lachin. This was a life changer for me professionally as I learned an incredible amount from them and decided that ultimately I wanted to do what they did- run a coordinating center for multi-center trials. So, while on the faculty at USF, I received a Physician Scientist Award from NIH (predated the current K awards) and used it to obtain a PhD in epidemiology at the USF College of Public Health.

At about the time I completed the PhD program, I started a coordinating center at USF; and when the ONTT ended and an epidemiologic study of the relationship of optic neuritis to multiple sclerosis began (the Longitudinal Optic Neuritis Study-LONS, which continued for 15 more years), the coordinating center was moved from George Washington to USF. I soon became frustrated by the bureaucracy of trying to build a coordinating center within the administrative constraints of a university, particularly a state institution, and decided to set up an independent nonprofit entity near the USF campus in 1993.

Since its inception in 1993, the JCHR Center's main focus has been serving as a coordinating center for multi-center investigator-initiated clinical trials, mostly NIH or foundation-funded. In view of my background as an ophthalmologist, one of our major areas of focus has been in eye diseases. Starting with LONS, JCHR became the coordinating center for the Herpetic Eye Disease Study (HEDS) funded by the NEI, which conducted several RCTs and an epidemiologic risk factor study in the 1990s. HEDS had 74 clinical sites, including both university-based and community-based sites. Thereafter, incorporating community-based sites into clinical trials became a major focus of many of our projects.

In 1997, I with two pediatric ophthalmologists Michael Repka at Johns Hopkins and Jonathan Holmes at the Mayo Clinic formed a network of pediatric eye care providers to conduct studies in eye disorders affecting children, called the Pediatric Eye Disease Investigator Group (PEDIG). PEDIG, which is funded by the NEI, has been an open network that allows participation by any site that has the requisite qualifications. The network includes both ophthalmologists and optometrists, and the collaboration of the two disciplines has been one of the rewarding aspects of PEDIG. Since its inception, 234 sites and 908 investigators have participated in PEDIG (currently 123 sites active in at least one protocol), with about 40% community-based and 60% university-based. As of 2018, PEDIG had conducted 47 protocols.

We followed the same model of an open-network with both academic and private practice sites in the Diabetic Retinopathy Clinical Research Network (DRCRnet), for which we were awarded the coordinating center grant in response to a Request for Applications (RFA) in 2001. In collaboration with the two other RFA awardees, Lloyd Paul Aiello at the Joslin Diabetes Center at Harvard who was the inaugural network chair, and Matthew (Dinny) Davis who headed the Fundus Photograph Reading Center at the University of Wisconsin, the network was established. Since its inception, 352 sites and 1307 investigators have participated in DRCRnet (currently 153 active sites in at least one protocol), with about 65% community-based and 35% university-based. Through 2018, DRCRnet conducted 31 protocols. In 2018, the network expanded beyond diabetic retinopathy to all retinal diseases.

JCHR also has been the coordinating center for two NEI-funded multi-center cornea disease clinical trials: the Cornea Donor Study (1999-2013) and the Cornea Preservation Time Study (2012-2017, for which coordinating center functions were shared with Case Western Reserve University), and since 2016 has coordinated a rare retinal disease international consortium funded by the Foundation Fighting Blindness. In 2018, returning to my roots in neuro-ophthalmology, JCHR became the coordinating center for the NEI-funded SIGHT study, a randomized trial comparing medical and surgical treatments for idiopathic intracranial hypertension.

That is only half of JCHR's history. The other half involves studies in diabetes, primarily type 1 diabetes (T1D). JCHR's involvement in diabetes research emanating from one of my three children developing T1D at age 12 in 1992. After a few years of daily learning about T1D at home, I decided to dedicate a portion of my time and our center's resources to diabetes studies. This decision came at a fortunate time in that Congress appropriated special funding for T1D research to the NIH, which put out several RFAs for coordinating centers. We were selected to be the coordinating center for the Diabetes Research in Children Network (DirecNet) in 2001, which over the next 12 years conducted numerous clinical trials and epidemiologic studies in children with T1D. Our DirecNet involvement led to the development of a close working relationship with the Juvenile Diabetes Research Foundation (now, JDRF), starting with JDRF funding to JCHR for a landmark continuous glucose monitoring clinical trial in 2007 and establishment at JCHR of an artificial pancreas studies coordinating center, which has become a major focus of JCHR's diabetes studies. Currently, JCHR is coordinating four NIDDK-funded artificial pancreas projects as well as JDRF and industry funded projects.

In 2010, the Helmsley Charitable Trust became a major funder of T1D research and provided support to JCHR to build a network of 80 adult and pediatric diabetes centers. This project included development of a longitudinal registry of about 35,000 adults and children with T1D and the conduct of 9 clinical trials and 16 other studies, utilizing the registry participants as a potential source for study participants. The registry datasets have been made public as a resource for researchers internationally. Mixed in with these T1D studies have been a few type 2 diabetes studies.

Over the years, I and our staff, which in 2021 exceeded 130, have had the good fortune to work with amazing groups of investigators and NIH and foundation program officers whose collaborations with us have been rewarding and impactful.

At the end of 2020 after 27 years of being JCHR's Executive Director, I decided it was time to step down and pass the baton to a new Executive Director. I was replaced by Adam Glassman who has been a statistician at the Jaeb Center since 2003 and the principal investigator for the DRCR Retina Network Coordinating Center. I am remaining actively involved in Jaeb Center projects as Medical Director while continuing as the Chairman of JCHR's Board of Directors.

Finally, people always ask where the name "Jaeb" comes from. It is not a philanthropic family but rather the initials of my children in order of age-Jody, Andy, Eric (**B**eck).