

Eos Connection 2005

Thank you to all who attended the 2005 Eos Connection conference in Cincinnati! Your participation made the conference a huge success!

Last week APFED held its third Patient Education Conference in Cincinnati, OH. Enrollment for the conference was 229 adults and 115 children. The Hypereosinophilic Syndrome Day and Psychology sessions with Dr. McGraw were universally heralded as useful, informative and worthwhile. We intend to build upon those additions and add new sessions as suggested by attendees.

The conference started out with our first ever "HES Day" dedicated to Hypereosinophilic syndrome. Dr. Marc Rothenberg began with an overview of eosinophils and associated disorders. Dr. Gerald Gleich came in from Utah to discuss the history of HES, its present treatment and potential future therapies. HES treatment certainly has come a long way!

The HES session was followed by the Eos Walk on Friday July 15th, which raised over \$16,000 for research. The funds were split 50/50 with the Cincinnati Center for Eosinophilic Disorders and the APFED Research Fund. Quite a turnout for our first walk in conjunction with our conference. We plan to make the walk an annual event. The approx. \$8000 going to the APFED research fund will cover our trainee travel grants next year. Dr. Rothenberg discussed the goals of the Cincinnati Center for Eosinophilic Disorders on Friday night during a very well attended reception following the walk.

Some of the Cincinnati Reds came to visit the children in child care- they spent what time they could signing autographs and posing for pictures. The kids went nuts to meet "real baseball players". We also hired a magician to perform on Saturday (the long day)- it helped ease much of the tensions for the children and made the days shorter and far more exciting. Some very strong friendships were forged, as well as mentoring between the children.

Also of note- APFED has co-written a children's book entitled Teddy the Tummy. The book was sponsored entirely by SHS North America. It is an educational piece for young children, the newly diagnosed and peer education. Copies were distributed to people who attended the conference. Additional copies are offered for purchase in our gift store.

Next year's meeting attendance is expected to increase significantly. We also plan to include a CME/CE course for doctors, nurses and healthcare professionals.

We must thank our MAB members who donated their time to the conference as well as express gratitude to the entire Board for its continued support. We cannot do this without the doctors- the families come to hear what is new, what is known, and what we hope will come to be. Special thanks to Marc Rothenberg for his ongoing, selfless personal time dedicated to this meeting.

Highlights from Friday

Beneficial effects of eosinophils include defense against parasites, cancers and aiding other immune responses. Eosinophils play a role in many disease processes including allergies, EGID, EE, idiopathic HES, inflammatory bowel disease, eosinophilic pneumonia, skin diseases and vasculitis. Dr. Rothenberg discussed the important role of eotaxin, IL-5 and other cytokines in mediating eosinophilic disorders. He explained the spectrum from IgE mediated diseases (typical allergic responses) to Non-IgE mediated diseases (celiac) and the difference between EGID and HES. The diagnosis of HES requires involvement of multiple organs, not just the GI tract.

Dr. Gleich discussed the history of HES, various manifestations of HES, and the lack of effective treatment until recently. He then discussed current treatments including imatinib (Gleevec), steroids, hydroxyurea and interferon-alpha. Imatinib, initially developed to treat leukemia, has improved the outlook for many people living with HES. The promise of anti IL-5 (mepolizumab) was also discussed.

Highlights from Saturday

Dr. Phil Putnam started the day with an overview of EGID, both allergic and non-allergic. He discussed the variation in symptoms by age, different treatment options (diet, medication) and ongoing research.

Dr. Konikoff discussed pediatric testing, endoscopy, biopsies, and allergy testing. Dr. Kushner described adult EGID from a medical perspective noting the differences in presentation and symptoms. Dr. Assa'ad discussed the link between food and EE. Dr. Spergel discussed studies of patch testing in EE from the Children's Hospital of Philadelphia. Skin prick and patch testing accurately identify offending foods in over 60% of individuals with EE. Over 95% of children with EE improve with an elemental diet. In the CHOP experience, very few children outgrow EE, but many do gain additional foods.

Dr. Rothenberg presented research from Cincinnati children's from their animal model of EE. Mice lacking IL-5 do not develop EE. He also presented data on gene expression in EE and the potential to develop better tests for EGID. Population studies from Hamilton County OH suggest an annual incidence of EE of 10 per 100,000 children. This is similar to more commonly known diseases such as Crohn's disease. Potential benefit for the investigational agent mepolizumab (anti IL-5) for EGID was also discussed.

Highlights from Sunday

On Sunday, Research databases and an understanding of how research is performed were discussed. Dr. James from the NIH presented information on the role of the National Institute of Health, organization into divisions, structure and grant application process. In 2004, the NIH awarded 47,468 research grants and 17,566 training grants with a budget of \$28 billion. Mandy Clemens discussed nutritional aspects of eosinophilic disorders. Dr. Kelly McGraw presented information on living with eosinophilic disorders. Stephanie Harlow gave a well-received talk on the patient AND parent's perspective on living with EGID.

Next year we plan to offer more on the parent and child's perspective of the disease, adults with EGID and psychological aspects of living with eosinophilic disorders.

Many excellent questions were asked and answered during the 3-day conference. Bottom line: There is much more to learn about eosinophilic disorders, their causes and treatment.

Radio Show Andrew Schorr had a live radio broadcast at the conference including interviews with Drs Putnam, Furuta and Rothenberg.

The radio broadcast can be heard on the web. Currently the programs with Philip E. Putnam, M.D., F.A.A.P. Ruthie Schorr, Marc E. Rothenberg, M.D., PhD, Joy and Chris Scheibneris available as a replay at: <http://www.patientpower.info/rCategories.asp?ID=Digestive%20Disorders>

Thank you again to all who attended for making *Eos Connection 2005* a huge success!

Please send suggestions for next year's conference to: mail@apfed.org

To volunteer for the 2006 APFED conference, <http://www.apfed.org/volunteer.htm>