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The 2022 ICAN Conference

The **2022 International Children's Anophthalmia Network (ICAN) Conference** was held in Downtown Philadelphia from July 15–17, 2022. Due to the COVID-19 pandemic, there was a break in the rotation that has seen this important organization gather every two years since the first meeting (also in Philadelphia) in 1999. The conference rotates to various cities, including San Francisco, Dallas, and Boston. This year the event was held in the City of Brotherly Love: Philadelphia.

The event was held at the Notary Hotel in Philadelphia, a world-renowned hotel and conference site. The ICAN clinic (where no cost eye evaluations and consultations were provided) was held at the Children's Hospital of Philadelphia (CHOP) and hosted by professionals from Children's Hospital of Philadelphia, LeGrand Associates Ocularists (Joe LeGrand, Susan Shore, and Savannah Wilt), and select independent ophthalmic professionals. Twenty-three families from nine states attended this important meeting.

All ocularists in attendance included Emily Barbour, Michael Hughes, Colleen Kelley, Kevin Kelley, Bridget Kinneer, Joe LeGrand, and Savannah Wilt.

A few of the conference speakers included:

- Genetic Discussions: Dr. Alanna Strong, MD
- Ophthalmology: Dr. Gil Binenbaum, MD
- Oculoplastics: Dr. Karen Revere, MD
- Education: Donna McNear, M.A.
- Ocularistry: Joe LeGrand, BCO, Kevin Kelley, BCO and Michael Hughes, BCO
- Overbrook School for the Blind: Beth Ramelia, E.D., CVI Specialist
- Encouragement-challenges for monocular patients:
Erin Rosenberg, M.A.

ICAN International's president, Ryan McGrady did an outstanding job organizing this important meeting. As president of ICAN for the last nine years, Ryan's dedication and positive energy is contagious. Erin Rosenberg serves as Vice President, organizing significant aspects of this meeting. Most eye care specialists, including ocularists, are familiar with microphthalmia, anophthalmia and coloboma as genetic conditions routinely seen. This informal meeting and the "safe rooms" (rooms where it's safe to ask any question, and to hear and see others who are or have experienced similar issues with anophthalmia-microphthalmia) are truly valuable to new parents.

As ocularists know, anophthalmia is rare. It is defined as the complete absence of the globe. It results from the failure of the optic vesicle to bud from the cerebral vesicle in the fourth gestational week. The terms "apparent" and "clinical" anophthalmia are used interchangeably when no globe is seen on clinical exam, but CT or MRI scans of the orbit reveal remnants of ocular tissue. Therefore "clinical" anophthalmia is severe microphthalmia.

Ocularists are also aware that microphthalmia may range from mild, with a slightly small eyeball, to severe, with a remaining eyeball associated with orbits and eyelids immature in size. Microphthalmia can occur anywhere from the fourth to the eighth gestational week depending on the severity.

A family with a newborn affected with this condition needs medical, emotional, and logistical support. Most medical practitioners have not dealt with this birth defect. Ocularists are oftentimes the eye care professionals that families visit first. Through informal discussions at the conference, anophthalmia and microphthalmia are used to the point that these terms do not sound foreign.

President McGrady commented “The greatest aspect of the ICAN meetings is how critical it is for families to connect. There were many inspiring moments at the ICAN sponsored childcare and the CHOP clinic where I witnessed firsthand emotions of families simply happy their child was supported by other children who had the same or similar conditions.” For the families and professionals who



International Children's Anophthalmia Network

International Conference
July 15-17, 2022

Children's Hospital of Philadelphia, Pennsylvania



attended, the 2022 Philadelphia ICAN Conference was a worthwhile experience.

For additional information regarding ICAN—the International Children's Anophthalmia Network, please visit www.anophthalmia.org.

ABOUT MICHAEL O. HUGHES

Michael Hughes, is a Board Certified Ocularist, who began working in prosthetics in 1982, and is a native of Pennsylvania. He attended Bucknell University in Lewisburg with the Pennsylvania Governors School for the Arts. He continued his education at Pennsylvania State University majoring in fine arts. Michael Hughes obtained a certificate in maxillofacial prosthetics technology from the Veterans Administration Medical Center in Wilmington, Delaware (in conjunction with Temple University). Mr. Hughes served with the Veterans Administration in St. Louis and Washington, DC, as Chief of the Artificial Eye and Restorations Clinic before settling into the suburban Washington, D.C. area. Michael Hughes primary office is in Vienna, Virginia. He is the principle ocularist at the University of Virginia and maintains offices in Richmond and Roanoke, Virginia. Michael Hughes is a Fellow member of the American Society of Ocularists. A special interest of his is a medical—charitable mission to El Salvador, C.A., with EyeCare International: www.eyecareint.org