Children's Low Vision Resource Center
By Appointment Only

Paula Korelitz
Outreach Director

Rosemary Blaszkiewicz
Parent Advisor

4064C W. 13 Mile Road
Royal Oak, Michigan 48073
1-800-788-2020
ropard@yahoo.com

ROPARD has available for parents, family and professionals many items that are useful for the development of children with retinopathy of prematurity and low vision.

Video I: Management of Retinopathy of Prematurity (VHS or PAL format) $30

Video II: Retinopathy of Prematurity, Current Issues (VHS or PAL format) $30

Videos I and II $55

Booklet: "Looking Ahead: A Parent's Guide to the Development of their Child with Retinopathy of Prematurity" $10

Brochures: "A Parent's Guide to Their Premature Infant's Eyes" Pkg of 100--$25. (available in English or Spanish)

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Package of 12 for $15.
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ROPARD is an association dedicated to eliminating the problems of low vision and blindness in children caused by premature birth and retinal diseases.

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For further information, please call 1-800-788-2020

Your tax-deductible contribution will be used to support the highest levels of clinically relevant research.

Susan Campbell,
Editor

Paula Korelitz,
Website Administrator

Should you have any questions regarding this issue, please contact ROPARD at 1-800-788-2020 or visit our website at http://www.ropard.org or e-mail us at ropard@yahoo.com

ROPARD Sight LINES

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The Newsletter of ROPARD
Timely Clinical Management Yields Good Vision in Retinopathy of Prematurity

Late Complications of Retinopathy of Prematurity

While the incidence of retinopathy of prematurity over the last twenty years is fairly flat, severe ROP has become more common in recent years. This is at least partly a consequence of the fact that ROP occurs in smaller and younger infants.

Globally, the leading causes of visual impairment include nutritional (vitamin A deficiency) and infectious (measles, ophthalmia neonatorum) causes. In Latin America, Asia and Eastern Europe where advanced neonatal intensive care is available, infant survival is higher resulting in a population of infants at risk for retinopathy of prematurity. ROP is here to stay, and with it adult retinopathy of prematurity as formerly premature infants survive into adulthood.

Prior to the 1940s, retinopathy of prematurity was essentially unknown due to the limited survival of premature infants. Prior to the 1980s there was no standardized treatment for retinopathy of prematurity. Infants born in this generation, therefore, generally did not have any treatment for ROP. This treatment, whether delivered by cryotherapy or laser, consists of destruction of the peripheral retina. Absent treatment, what took place was the natural "auto involution" of the proliferation which characterizes ROP.

Conversely, children born in the era of the CRYO-ROP study (1980s) or later, underwent procedures whereby the peripheral non-vascularized retina was destroyed in the interest of preserving central vision. This newer generation of infants – though they have the benefit of treatment for retinopathy of prematurity – tended to be smaller and sicker, often with other prematurity-related problems such as lung disease, intracranial hemorrhage and the like.

Formerly premature adults with ROP are susceptible to ocular problems apart from ROP. Cataract and glaucoma are two examples of eye pathologies more commonly seen in formerly premature adults than adults who were not premature.

Sixth Children's Vision Award

The recipient of the sixth Children's Vision Award will be honored on Saturday May 8, 2010 at the Detroit Institute of Arts, Detroit, Michigan. Mark your calendar and plan to attend the Children's Vision Award ceremony.

Late Complications of Retinopathy of Prematurity (Cont.)

From the retinal perspective, formerly premature adults who had retinopathy of prematurity are more prone to retinal detachment and changes in the peripheral retina which can predispose to retinal detachment. Furthermore, they can be a bit more challenging to fix. Retinal detachment repair is successful in adults who were not formerly premature on the order of 90 percent of the time with a single operation. Conversely, formerly premature adults who had retinopathy of prematurity who go on to develop retinal detachment are successfully repaired in a single operation in approximately 10 to 15 percent of the time.

ROP is here to stay as new "waves" of ROP arise in countries where neonatal intensive care services are newly available. There are two different generations of retinopathy of prematurity – those prior to the 1980s who were untreated, and those born since who were likely to have been treated. Ocular complications occur in those who were formerly premature beyond the "acute ROP" seen in infants. In this sense, a child born prematurely is forever premature with regard to the impact of prematurity on the ocular structures. Formerly premature individuals should be diligently monitored for cataract, glaucoma, and retinal problems throughout their lives in order to maximize the likelihood of maintaining optimal vision.

Eric Cook, A Futuristic Designer

Eric Cook views the world with an unquenchable curiosity and a lively sense of humor. It was not always so easy. Born prematurely to Bud and Cathy Cook, in 1982, Eric weighed only 1½ pounds at birth. He spent the next six months in Children's Hospital in Detroit where his eye development was monitored.

The years that followed were a challenge for the family. Eric's premature birth affected his ability to eat, breathe, speak, and his fine motor skills. It wasn't until he was about three years old, and he discovered the salt on a corn chip, that he began to eat on his own. At four years old, he donned glasses to correct a lazy eye. Speech was also difficult for him.

When Eric entered kindergarten, he spoke only with vowels, causing a communication impasse with his peers and teachers. However, by second grade, he was speaking with more fluency and being understood. Because of his speech impediment, Eric was viewed by his teachers as 'slow', his peers as 'different' and treated as such. In addition, at the age of 11, he was diagnosed with Crohn's Disease. In sixth grade, Eric developed his interest in art and, and his work was hung in a local art show. His favorite medium is pencil and paper and reflects an interest in futuristic creatures and designs. With stubbornness and perseverance, Eric graduated from 12th grade with good marks and an enduring interest in archeology and mythology.

Three years ago, the vision in Eric's right eye 'went dark'. On examination, a detached retina was discovered, which was subsequently reattached. Since that visit, Eric has been treated for glaucoma and a cataract in his right eye. Presently, his left eye, which has a cataract developing, presents a blurry image.

Despite all of these problems, Eric is a voracious reader—often tackling an encyclopedia volume for light reading. In addition to drawing, writing fantasy fiction occupies his time. He loves to travel and when possible, he and his parents attend conventions for futurist toy collectors where he promotes his designs. Having developed the strength to deal with many difficult situations, Eric lives with an upbeat and positive attitude.

Sarah Blake

Sarah was diagnosed with ROP (then called retrolental fibroplasia) at five months old. Now 37, she has undergone six surgeries on her right eye. These have helped to maintain some useful vision, although her vision has diminished over time. For Sarah, it is important that a doctor be honest and have a positive attitude about blindness. From a young age, she has been prepared for the possibility that she will lose her vision.

Sarah learned both print and Braille. Because it had to be large size, print was impractical for schoolwork. By junior high, she was using Braille exclusively. She also learned how to use a white cane and was trained with a guide dog. She now has her fourth dog, Loretta. In elementary school, Sarah received services in a resource room and later from an itinerant teacher of the visually impaired. During high school, she took full course loads without direct services. At college she took full course loads that often required creative solutions to meet her needs.

Sarah studied music, business and Christian ministries in her first two undergraduate years. Although today more resources are available for music students, when Sarah wrote a music theory exam, she had to play the answers on the piano instead of writing them in music notation. She eventually majored in psychology and minored in special education. Linguistics was a main interest, but there was no Braille representation of the International Phonetic Alphabet. After four semesters of Spanish using Braille textbooks, her study was stalled by a lack of accessible textbooks.

After graduation, Sarah's search for full-time employment was long and unfruitful, though she did hold several part-time and freelance jobs. For three years she worked in the child care ministry for a local church and as technical writer with a manufacturer of computer products for people with disabilities. Ultimately, she decided that she needed to return to school.

In 2006, Sarah began graduate studies in theology. This included Hebrew; her knowledge of computer software was useful to configure her computer to display Hebrew in Braille. She has completed two years of Hebrew study and one year of Greek with plans for a second year of Greek and a job as a teaching assistant. She will graduate with professional distinction in Hebrew.

In the mid-1990s, a Braille version of the International Phonetic Alphabet was developed. A blind person can now study linguistics. Advancements in computer technology make it possible to develop new Braille systems for languages that do not currently have them.

In the future, Sarah's plans include making Braille available in more languages, some public speaking and writing. She hopes to take a doctoral program in Near Eastern languages, including biblical studies and related literature and that her work will eventually include other ancient literature. Her objective is to make the world of classics and biblical studies more accessible to people who are blind.

"I am often amazed at the changes in technology that have taken place during my lifetime," says Sarah. "I am old enough to remember attending college without the benefit of much technology—I hired students to read for me during my first few years and often suffered poor grades due to finding readers late in the semester. I have not used a reader for any of my seminary coursework, including exams! Everything can now be done on computers. It is a truly amazing time to be alive."

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