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Children's Low Vision Resource Center

By Appointment Only

Paula Korelitz
Outreach Director

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Parent, Educator and Nursing Staff Seminar Videos

The Association for Retinopathy of Prematurity

VIDEO ONE

September, 1998 Video: (1-1/2 Hrs)

Management of Retinopathy of Prematurity

Stages, Zones and Clock Hours of ROP
Related Disorders
Treatment Modalities
Long Term Considerations

The presenters are:
Patrick Droste, M.D.
Edward O'Malley, M.D.
John Roarty, M.D.
Michael Trese, M.D.

VIDEO TWO

May, 2001 Video: (2 Hrs)

Retinopathy of Prematurity Current Issues

Identification of Pediatric Retinal Diseases
New Medical Intervention Modalities
Rehabilitation for Children with Advanced ROP
Up-to-date information on current research

The presenters are:
Patrick Droste, M.D.
Jack Baker, M.D.
Michael Trese, M.D.

\$10.00 can be considered a tax-deductible contribution for each tape purchased.
Videos can also be purchased on our secure website at www.ropard.org
Michigan residents add 6% sales tax

NAME _____		
ADDRESS _____		
CITY _____	STATE _____	ZIP/POSTAL CODE _____
COUNTRY _____		
VIDEO ONE: _____ @ \$30.00 = TOTAL \$ _____	Please mail to: ROPARD P.O.Box 250425 Franklin, MI 48025	
VIDEO TWO: _____ @ \$30.00 = TOTAL \$ _____		
VIDEOS ONE & TWO: _____ @ \$55.00 = TOTAL \$ _____		
_____ CHECK _____ MASTERCARD _____ VISA	Please add \$5.00 for shipping and handling outside the U.S.	
CREDIT CARD NUMBER _____	EXP DATE _____	<i>PAL and SECAM format tapes are available. Contact ROPARD for further information.</i>
SIGNATURE _____		

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

Your Donation Can Make A Difference!!!

Show your concern for this cause by donating to:
ROPARD, P.O. Box 250425, Franklin, Michigan 48025

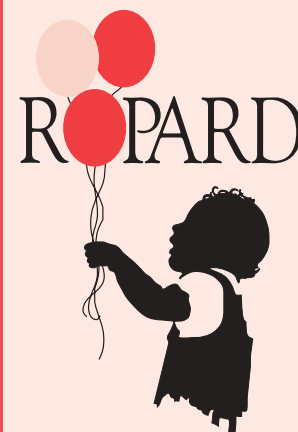
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**For further information, please call
1-800-788-2020**

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



Liz Nellis,
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



Pediatric Retinal Diseases DNA Library

Many retinal diseases affecting newborns and children appear to have genetic causes and can occur in families. Others may also have genetic causes which have eluded us for many years. ROPARD supports a Pediatric Retina DNA Library at William Beaumont Hospital, funded by a generous grant from Margaret J. Walters. This laboratory will enhance our efforts to better understand retinal diseases. Hopefully, these studies will result in gene therapy or other modern treatments. The library will collect DNA samples from patients with a variety of pediatric retinal diseases including those having more known genetic mutations such as congenital retinoschisis and familial exudative vitreoretinopathy. Studying and comparing a large number of genetic samples may uncover clues to the causes of other

diseases as well. These diseases include retinopathy of prematurity and persistent fetal vasculature syndrome and Coats' disease, previously not thought to be the result of genetic mutations.

Kimberly Drenser, M.D., Ph.D. has been instrumental in setting up the pediatric retinal DNA library, and she has proposed specific genetic therapy potentially for the problem of congenital retinoschisis. This disease has a wide spectrum of presentations and can cause both legal and total blindness. We hope that this DNA library will be a place where scholars interested in specific diseases may come to analyze a large number of genetic samples and that this may lead to many new therapeutic interventions.



2004 Children's Vision Award

On May 5, 2004, ROPARD will host the next Children's



■ Teresa Nascimbeni

Vision Award dinner. Previous recipients are Frank Kelley, long-time Attorney General of the state of Michigan, and Dr. John Baker, Chief of Pediatric Ophthalmology at Children's Hospital and William Beaumont Hospital, Royal Oak. Both are founding members of ROPARD and have contributed greatly to the activities of the ROPARD organization.

This year Teresa and Sergio Nascimbeni will be honored for their contributions to children's vision. For a decade, Teresa and Sergio have been involved with children who come to the United States for pediatric retinal surgery. In addition to physically arranging for nearly 100 children to come for a multitude of surgical interventions, their caring spirit has led them to become involved with

these families, almost adopting them as their own.



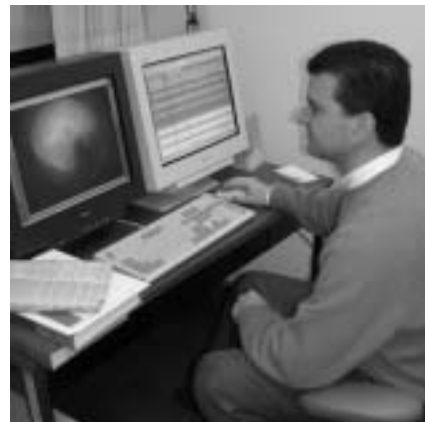
■ Sergio Nascimbeni

Teresa and Sergio will be honored as the recipients of the Children's Vision Award for their decade of selfless accomplishments.

Instrumental in starting a training program at William Beaumont Hospital for Italian physicians to obtain pediatric retinal expertise, Teresa and Sergio are well-known members of the Italian community. The host committee for the 2004 Children's Vision Award Dinner includes Dr. Nicola De Santis, Consul of Italy, in Detroit.

For more information about ROPARD or to make reservations for the 2004 Children's Vision Award Dinner, please call 1-800-788-2020 or visit our web site at www.ropard.org

Photo-ROP Study



■ Dr. Antonio Capone, Jr.

ROPARD has been funding the Photo-ROP Study for the past several years. This study has been designed by Dr. Antonio Capone, Jr. to determine whether or not photographic screening for retinopathy of prematurity could

be effective. Over 3,000 photos have been received from all over the United States as well as Canada, Ireland and Great Britain to the ROPARD study center at the William Beaumont Hospital, Royal Oak campus. The study has received nearly \$300,000 in grant support from ROPARD and The Lincoln Foundation to carry out its mission. Hopefully to be released soon, the results of this study should give centers throughout the world photographic screening guidelines for retinopathy of prematurity. Improved screening will enhance efforts to reduce blindness from retinopathy of prematurity. This technique may also be useful in screening for intraocular cancer or other pediatric retinal diseases.

ROPARD Announces Future Publications

In response to concerns addressed by families of children with retinopathy of prematurity, ROPARD is in the final stages of producing two new publications. The first, "What Parents Need To Know About Their Premature Baby's Eyes", was developed to be distributed by Neonatal Intensive Care Units to parents of all premature babies. This booklet will briefly explain the stages and interventions of retinopathy of prematurity and stress the need for timely follow up of these infants. "Looking Ahead: A Parents' Guide to the Development of their Child with Retinopathy of Prematurity" will provide milestone guidelines for parents and suggestions for activities to help children acquire those milestones. Also included will be graphics to assist with vision stimulation. This booklet was funded by generous grants from the Delta Gamma Foundation and the Beaumont Foundation.

Notification of availability of these publications will be posted on our website at www.ropard.org and emailed to all individuals who have joined our email mailing list.

What's New At The Children's Low Vision Resource Center?



■ Roger McCarville from PBS interviews parent, Dawn Peifer about the Children's Low Vision Resource Center.

At this time of year it is appropriate to give recognition to all of the unseen angels who have given of their time, special talents and money which allow us to provide free services and materials to families who visit the Children's Low Vision Resource Center.

One special angel purchased our multi-function machine which allows us to make copies of needed documentation for the families who visit the center. This angel has also paid for cable internet access, for a quicker connection which frees up our telephone line.

We have been blessed to have the expertise of a volunteer who has adapted several of our commercially available toys so that we can turn off the sound. This enables us to explore whether a child is attracted to that toy because of the sound or whether the child is using his or her vision to look at the toy's flashing lights.

Delta Gamma members have been our ongoing and committed volunteer base. They were instrumental in the creation of the center and have continued to lovingly sew Delta Gamma Baby Blankets, create texture boards and purchase trays to give to families.

The Children's Low Vision Resource Center is to be featured on a segment of "Disabilities Today" on PBS. The segment is scheduled to air on Tuesday, December 2, in Michigan, several other states and Canadian provinces. To see if the segment is available in your area go to www.disabilitiestoday.com and check the "Where to Find Us" link. There will be a second showing of the segment in the Spring of 2004.

It is our hope to increase the space of the Children's Low Vision Resource Center in 2004 so that we can include more area to display toys, books, and videos and include an area devoted to high tech equipment.

Ropard Offers our First Holiday Greeting Cards



See this wonderful card in its full-color glory on our website at www.ropard.org. The cards are \$15.00 for a box of 12 with 50% considered a tax-deductible contribution to ROPARD. To place your order see our secure online order form at our website, or download an order form to be mailed in.

About Our Artist

Annabelle is a delightful seven year old who lives in Polk City, Iowa with her mom, Gina, her dad, Nick, and her two brothers, Nicholas, six, and Sam who is nine months old. Annabelle is in the first grade at Holy Trinity in Des Moines, where she receives the

services of a teacher of the visually impaired for one hour a day.

Annabelle created her snowman by using three different textured plastic circles for the body of the snowman to which paint was added. She had a little assistance adding the fine details to her snowman, but the creative process was all hers!



Besides being a budding artist, Annabelle loves to play the piano and read books. Her favorite books are from the Junie B. Jones series. Annabelle's mom told us that she usually borrows her books from the Iowa School for the Blind, so ROPARD sent Annabelle a collection of Junie B. Jones books from Seedlings. That way, she can read her favorite books over and over again.