



## Retinoschisis

**C**ongenital X-linked retinoschisis is a leading cause of legal blindness in full-term infants in developed countries. It is inherited through an unaffected mother and generally affects young boys. Its severity varies and until recently has been thought to be composed of only two types. We have now identified and outlined four types of retinoschisis by using both clinical testing and optical coherent tomography testing, which gives a cross sectional picture of the retina. It shows the basic disease process, which is a splitting of the retina into multiple layers.

As part of a special ROPARD research effort, two categories of congenital X-linked retinoschisis patients are being studied and two separate types of therapies are being sought.

One program targets the elimination of congenital X-linked retinoschisis from families. The obligate carrier mother's good X chromosome is blended with the

father's X or Y chromosome by invitro fertilization. The mother then carries the unaffected child to term.

The second program involves the population of patients who are already affected by congenital X-linked retinoschisis. These patients are being studied in an attempt to re-establish a connection between the split retinal layers. This study is looking at the content and structure of the schisis cavity in hopes of creating a new protein that can connect the two layers and perhaps establish vision in these areas of the retina that have been unable to function due to the splitting of the retinal layers.

Both of these studies are being pursued by support from the ROPARD Association. We are hopeful that they will allow vision for already affected children and eliminate the concern of congenital X-linked retinoschisis from families in the future.

## Meet the Van Houtens



Ben and Amy with their babies in June.

**I**n a ten-day period in January 2004, the Van Houten sextuplets were born in Grand Rapids, Michigan. John arrived January 7, followed on January 16 by his brothers Gerrit, Nolan, Peyton, and sister, Samantha. Finally, four hours later on January 17, a second sister, Kennedy was born. All were 3 1/2 months premature. Nolan was the heaviest at 2lb. 1oz.; Gerrit was 1lb., 11oz.; John 1lb., 8oz.; Sammy 1lb., 7oz.; Kennedy 1lb., 5oz. and Peyton 1lb., 4oz.

I was lucky enough to visit with the family in November.

Five of the children required corrective eye surgery which was not available ten years ago. Nolan was the exception and

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## Meet the Van Houtens continued from page one



Gerrit



John



Nolan



Sammy



Kennedy



Peyton

Gerrit, John, Kennedy, Peyton, and Samantha required laser surgery. John also had a vitrectomy and removal of the lens in his right eye. Now he wears a contact lens in that eye. The surgeries were performed by Dr. Trese in Royal Oak and Dr. Droste in Grand Rapids. All the babies are responding well since their surgeries. Twenty years ago, five of these children would have been visually impaired. Today, because of pediatric retinal research, all will have functional vision.

After many stressful months, Amy and Ben brought home the last of the six babies to Hamilton, Michigan. Today, with the help of friends from their church and Amy's mother, Sandy Reimink, the children, now 10 months old, are thriving in a loving and stimulating home. Run like clockwork that would put the military to shame, the children are fed, bathed, nursed, played with, exercised, cuddled, and cared for. A schedule is kept on the kitchen counter—a binder with sections for each child—so all the caregivers know what needs to be done each day. And of course there are the other chores, laundry, cleaning up, preparing formula, and food. Amy and her helpers manage with a remarkable aplomb. In addition to all of the appointments that the

babies must keep, a physical therapist comes to the house once a week to supervise the physical development of the babies.

A relaxed atmosphere reigns in the home. Although they are not identical, the children are all good-natured, curious, and talkative. They wake each morning after twelve hours of sleep in cheerful happy moods. Their day begins at 7 am with their first feeding—three babies eat four times a day and three eat five times a day. Gerrit and John have had eating problems, but with creative care, they too are thriving. Surprisingly, John weighs the most at 20 pounds.

They're all sweet, they're all individuals. Amy and Ben have been presented with an enormous challenge and are meeting it with serenity and good humor.

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## Our Parents Reach Out to Each Other

Like many parents who visit ROPARD's Children's Low Vision Resource Center, Dawn Peifer, mother of three-year old Kimmie Drudge, knew of no resources in her home state of Virginia. Dawn was highly motivated to correct the situation.

When she returned to Virginia, Dawn and her husband John Drudge, sought to raise awareness of the needs of children with retinopathy of prematurity (ROP). Dawn created a support organization in Virginia for the families of children with ROP. In 2003, Child's Hope for Sight (CHS) was formed to help those families and the professionals working with them. In the meantime, by putting the ROPARD logo on his racing car, John brought ROPARD into the spotlight.

As Dawn began to meet and network with other families, she soon realized that there was a great need for support, networking, and information for families with children suffering from all types of visual impairment. She broadened CHS's focus, incorporated, and eventually became the President of the Virginia Chapter of the National Association for Parents of Children with Visual Impairment (NAPVI).

CHS has continued to grow. It has also created a website to disseminate much needed information and can be found at [www.childshopeforsight.com](http://www.childshopeforsight.com).

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## ROPARD Receives Generous Contribution to Aid in Retinoschisis Research



Oscar Boonshoft

ROPARD is pleased to acknowledge a contribution in the sum of \$50,000 from Mr. Oscar Boonshoft.

This money will be used to find a cure for the most common form of juvenile macular degeneration, known as congenital X-linked retinoschisis. With this seed money, ROPARD will begin the long process which is targeted to find a

cure for this genetic visual impairment.

ROPARD and the families affected by congenital X-linked retinoschisis appreciate this generous contribution.



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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.  
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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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