



## James D. Lauderdale, Ph.D. Aniridia's Sherlock Holmes

It's a mystery - but not one found in a book or a movie or on television. It's a medical mystery, and for Dr. Jim Lauderdale, Associate Professor at the University of Georgia, the mystery involves understanding the central nervous system well enough to be able to develop treatments for some genetic disorders affecting the brain, vision, hearing, and smell.

One specific 'case' that Dr. Lauderdale has been working on is trying to uncover the role that a gene called Pax6 plays in the genetic eye disorder aniridia. Aniridia afflicts one in 60,000 babies born each year, and is charac-

terized by deficiencies in the iris of the eye. These deficiencies lead to reduced translucency

ciliary body. These effects result in poor vision early in life and can lead to blindness later in life.



James D. Lauderdale, Ph.D.

(amount of light that enters the eye), scarring, cataracts, and insufficient development and maintenance of the retina and

Dr. Lauderdale has been studying the Pax6 gene and its role in aniridia for over 12 years. With help from some collaborators he is working to develop a technique that he hopes will offset the deficiencies caused by the

mutations, or random changes, in the Pax6 gene that lead to aniridia. "We cannot prevent aniridia from occurring, but we

can work to correct the negative effects that are caused by aniridia" says Lauderdale. "The goal of my research is to find a way to maintain the clear vision that most young children have with aniridia."

Dr. Lauderdale is on the trail of some promising leads, but it takes time and money to support the research. Vision for Tomorrow is proud to be able to assist his efforts. Board member Wendy Baum comments "Dr. Jim Lauderdale is on the forefront of understanding the genetic components causing aniridia and its associated conditions. We are thrilled to have the opportunity to support his efforts by providing him and his team with a \$15,000 aniridia research grant. Good luck!"

## More than a wedding

Weddings bring gifts of all kinds-silver, china, stemware and more.

But for one couple, you can add contributions to the Vision for Tomorrow Foundation. For Sara and Ryan Kirkwood, there was more to gift giving than the traditional gifts.

They decided to let their friends and family make contributions in their name to VFT. On January 3rd, 2009 many of their friends did just that.

"The research that is being done through VFT is important, and is particularly meaningful to us.



The bride and groom.

Ryan was born with albinism. We are so grate-

ful for all of our family and friends, who have been so generous."

VFT Board Member, Susan Ballis echoes Sara's gratitude- "We are delighted that Sara and Ryan chose VFT as a gift recipient, and welcome others to celebrate their event with contributions to VFT!"

## Dear Friends:

What does The Vision for Tomorrow mean to me? It means HOPE. It is the hope that someday my child, and others like him, will be able to have 20/20 vision. Tyler, who is currently seven years old, was born with aniridia and glaucoma. Throughout his short life, we have traveled throughout the United States visiting the best doctors to help treat his conditions. He currently has very little

vision in his right eye and is about 20/100 in his left. Despite his low vision, Tyler is a very good ath-



*Rich and Tyler*

lete who can hit a pitched baseball without a problem. This is great news for

the moment, but his future prognosis is not so positive. Eventually, his eyesight in his "good eye" will begin to deteriorate. Continued research that contributes to medical advancements is the only way to help stem this tide. This is why organizations such as The Vision for Tomorrow mean HOPE for Tyler and children afflicted with low vision. I am aware that these tough economic times make fundraising a difficult proposition. However,

The Vision for Tomorrow is continually investing in research that will someday help our children see the world in the way that most of us do. To Tyler, it will help him see the small print in a book, a golf ball flying through the air and provide the ability to drive a car. As his father, this HOPE is what motivates me every day! Any contributions to our cause would be greatly appreciated.

**Rich Baum**



Discount Day at Just Between Friends and Madison and Friends on February 5th helped to raise over \$1,500 for VFT. Thanks to these two Deerfield stores and to all of the shoppers!

You can make a difference in the lives of those with visual impairments!

We can do it together, and you can call the shots in our **"Committed Contributor"** program. Tell us what aspect of visual impairment interests you and **85% of the funds raised through your efforts will go directly to your low vision cause.** We will help promote your fundraiser via our website and newsletter. Team with us today and together, we can make a difference! Give us a call at **847-877-9077.**

## Board Members

Susan Ballis, M.D., *Co-Founder*

Jon Ballis

Richard Baum

Wendy Baum

Beth Kaufmann

## Our Mission

The Vision for Tomorrow Foundation seeks to empower people with low vision to have the confidence and ability to achieve their dreams.

## Our Vision

Our goal is to provide funding for research initiatives, to support and create educational resources and to generate public awareness regarding conditions causing visual impairment, with a focus on genetic disorders causing low vision at birth. Additionally, we aspire to be recognized as the "go-to" source of information for those seeking to learn more about these conditions.

## Heather Kirkwood

**H**er parents learned that she was born with albinism when she was three months old. At 19, she was diagnosed as having Hermansky-Pudlak Syndrome (HPS), a type of albinism, which is at the root of a number of her physical problems. For some, it includes a bleeding tendency, Crohn's Disease-like symptoms, pulmonary fibrosis and arthritis to name just a few conditions. For Heather Kirkwood, it was all of the above.

Heather's parents, Bob, a career military officer in the Air Force and Susan Cockerill, who was working for the Red Cross, met in Vietnam.

As with most military families, home could be anywhere in the world. That pretty much explains why Heather, who was born in Enid, Oklahoma spent only 19 weeks there. Three years later, her brother, Ryan (see page one story) was born. He, too, has albinism.

There's a one-in-four chance that a second child in the family will also have albinism, which occurs when both parents carry the recessive gene which causes it.

When she was 12, her parents divorced. Heather and Ryan lived with their mother in Wichita, Kansas for two years while their mother was in graduate school. Susan, who loved seeing the world, took a job as a teacher

Hermansky-Pudlak Syndrome with its package of physical possibilities. Most college students have enough stress and problems without the physical ones. Heather dealt with them as they presented themselves. "You can choose how to live your days-be miser-

work full-time in an office. She is now trying to find a grant so she can work for the HPS Network at home.

Today, Heather is living in Overland Park, Kansas and managing on her own. Her distance vision is 20/300 and 20/400 up close. Glasses don't help. She's in a blind trial study at the National Institutes of Health for those with pulmonary fibrosis, a condition which may progress to the point of requiring oxygen and possibly a lung transplant. Heather doesn't know if she's getting the medication or a placebo.

Managing her medical bills on her COBRA insurance is daunting. The bills are "eating me up alive."

She has one very important bit of advice for the parents of children with albinism and HPS. "Have your child tested for the bleeding disorder as soon as possible. If your child has an accident, doctors will understand the cause of the bleeding and treat the patient appropriately." For information about a free blood test to determine if your child has the bleeding factor, contact the HPS network at [www.hpsnetwork.org](http://www.hpsnetwork.org).



Heather and her brother Ryan (right).



Heather Kirkwood.

with the U.S. Defense Department in Germany. Heather graduated from high school in Germany and decided to go back to the states for college. Journalism would be her major. The University of Kansas would be her college.

Then came the

able or not," comments Heather. She picked "not" and in 1996 graduated from the University of Kansas with a bachelor's degree in journalism.

In the next few years, Heather became a senior editor of Expo Magazine, a trade show's publication. Eventually, she had to leave the job because her physical problems made it impossible for Heather to

## An untold story

You haven't read it in the newspapers or seen it on television. It's one of those stories that develops in a far-off land but has particular significance to the Vision for Tomorrow Foundation.

In early January, an internet story detailed the killing of an eight-year-old boy with albinism who was killed in Burundi. His limbs were smuggled into Tanzania to be used by witch doctors to make potions. The story further reported that at least 35 children with albinism were killed in Tanzania in 2008. (The incidence of

albinism in South Africa is about one in 4,000 people. In the US, the National Institutes of

youngsters with albinism in Dar es Salaam decided to show the world that they could have fun and

live peacefully and enjoy life like everyone else. It's their way of overcoming the fear and stigma suffered by those with albinism.

Their story resonated with us at the Vision for Tomorrow Foundation. "When we came across this story, we felt it was important to help this team out. We thought the Albino Magic Soccer Team, playing outdoors, could use some sunscreen. We wired them a check for \$1,050 to purchase a season's worth of sunscreen," comments Board Member Susan Ballis.



*A team thanking Patric Nyembela (EATV) for giving a football.*

Health reports that there are fewer than 200,000.)

These atrocities continue today. Undeterred by the killings, a group of 20

formed the Albino Magic Soccer Team. Their objective was to show that young people with albinism have a right to

### The Vision for Tomorrow Foundation

655 Deerfield Road, Suite 100 - #130  
Deerfield, IL 60015-3241

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