

The Chris Albrecht

# HOPE FUND

(Helping Other PEople)



Chris Albrecht, former
AFI board member, who
years ago created the
HOPE (Helping Other
PEople) Fund, led his life
with his Christian values
of helping others and with
the inclusionary belief that
everyone is important -



everyone has a purpose. Upon his death, the HOPE Fund was renamed in his memory and with the purpose of following his life values of helping others in need both through acts of kindness and financial assistance gifts.

## Donate to the HOPE Fund

If you or your company would like to donate to the Chris Albrecht HOPE fund, please go to http://weblink.donorperfect.com/HOPE\_HELP to donate online, or mail a check to our address.

Thank you for supporting our mission to improve the lives of people living with Aniridia Syndrome!

# **The Chris Albrecht HOPE Fund Policy**

Each year a designated amount of funds will be allotted to the Chris Albrecht HOPE Fund specifically for areas designated under

Category 1 - non-medical assistance gifts and Category 2 - medical assistance gifts.

To receive assistance, a completed application will be required. Only fully completed applications will be reviewed and vetted quarterly on a case by case basis by the Chris Albrecht HOPE Fund committee and the AFI Board of Directors. Copies of the person's most current tax return will be required to accompany the application as this is awarded on a "financial need" basis.

Gifted funds will be paid by the Aniridia Foundation International (AFI) to the billing entity in most cases. Specific details on the assistance gifts, timeline for AFI payment and the expiration date for the gifted funds to be used will be shared depending on which category and area is being applied for. Before assistance gifts are paid, gift recipients will need to sign an acknowledgment of their acceptance of the assistance, their understanding of the rules, including the number of times the gift recipient can receive assistance, and the rights to use their story for promotional and marketing purposes. AFI agrees to change names in the story to protect identity if the gift recipient requests it.

## **Schedule of Application Review**

February 15 deadline – gifted by March 31 May 15 deadline – gifted by June 30 August 15 deadline – gifted by Sept 30 November 15 deadline – gifted by Dec 31

# **Assistance Categories and Sub Areas**

### **Category 1 - Non-medical related assistance**

#### a) Assistance with purchasing adaptive equipment

This includes a committee member helping them to navigate options (state agencies, voc rehab, etc.) If a person works through all options without success, and no other options are available, financial assistance to help offset the cost of the item purchased will be considered.

# b) Assistance in attending the AFI "Make a Miracle" conference

This assistance is available to help offset costs for an individual with Aniridia Syndrome (AS) to attend the conference to learn from the expert physicians, researchers, vision professionals and meet others with Aniridia Syndrome (AS) and their families. At conferences, there is a child care and teen program for those with AS and their siblings while parents learn. Some conferences have the "See the Experts" clinics available. Assistance areas: offsetting travel, lodging, or child care costs.





#### c) Assistance with peer counseling

This area involves peer counseling for people with AS by those with extensive knowledge and experience in Aniridia Syndrome. It is not meant to be for professional mental health counseling (see Category 2) as sometimes it just helps talking to someone who has walked in your shoes and who truly understands. May get them involved in an AFI group support after assessing needs.

### Category 2 - Medical related assistance

#### a) Assistance with genetic testing

For those with AS who have never been genetically tested, or having special circumstances, AFI can help with the expensive cost of specific genetic testing for Aniridia Syndrome through their Medical Registry program. The genetic results are then included with the individuals own Medical Registry file which gives them additional benefits by just keeping their file updated yearly.

# b) Assistance with needed yet uncovered devices

Currently, some insurances do not always cover specific devices like iris implants or therapeutic Hydrophilic Contact Lenses (Corneal Bandage) which are medically necessary for those with artificial corneas or for the treatment of severe ocular surface diseases including corneal stem cell deficiency and Aniridia. While we hope to help change this way of thinking by the insurance



companies, until then, we want to help offset costs for those who truly need them however, cannot afford them.

### c) Assistance with needed yet uncovered surgery costs by an approved subspecialty surgeon experienced in Aniridia Syndrome

Unfortunately, some insurances like HMO's and Medicaid programs do not always allow you to travel to have surgery to be done by an expert in AS. We have seen that the best outcomes to retaining vision are those who seek successful surgery care from those experienced in AS and their subspecialty. If it is deemed necessary for you to have a surgery to retain vision (i.e. glaucoma, etc) and you are not covered at a specialist facility with AS experts or cannot afford the out of pocket surgery expenses, you can apply to receive financial assistance to offset your costs.

# d) Assistance to see an out of state expert subspecialty physician in Aniridia Syndrome

The special and successful treatment of rare disorders like Aniridia Syndrome (AS) is difficult for some local doctors with little experience in it. We encourage people to have local glaucoma, cornea, pediatric and retinal ophthalmologists to be monitored, to assist in surgery follow ups, and/or to have doctor to doctor consulting with the AS experts. However, it is also important to have a physician in the specific subspecialty area who has extensive experience and the latest knowledge of AS for an expert opinion, needed surgery or overall guide in the management of Aniridia Syndrome. Lodging or travel assistance is available

# e) Assistance for those not insured or unable to afford mental health counseling for depression, anxiety, etc.

Since the PAX6 gene affects the development and maintenance of the central nervous system and parts of the brain, it is understandable there may be those with AS who suffer mentally. Autism Spectrum Disorder and anxiety have been seen in some with AS, and also depression in those dealing with loss of vision or independence. Especially in today's world, we want to help those with AS who cannot afford and need counseling help, and to let them know they are important.

To request a Chris Albrecht HOPE Fund application, email AFI at aniridia@make-a-miracle.org or use our Contact Us form on our website at make-a-miracle.org.



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