

What we do

Medical Professional Awareness Opportunities

The Conley Cushing's Fund underwrites opportunities for medical residents and professionals to learn more about Cushing's Disease through panel discussions and lunch and learn sessions.

Annual Kickin' Cushing's to the Curb Reception

The Fund holds an annual event in November at the Hershey Country Club. Thanks to the generosity of hundreds of sponsors and donors, the Fund raises awareness and support to further the mission of the Conley Cushing's Disease Fund, fiscal sponsor TFEC.

Cushing's Disease Support Group for Patients and Family Members

The Fund is always happy to welcome any Cushing's patient no matter where they are on their medical journey. We meet several times a year and have become a strong local resource for one another. *For more information or to join us, contact support@kickcushings.com*

"This Cushing's support group means those of us living with this rare disease are no longer alone. At times it can feel as if the medical community doesn't get us, our families and friends don't get us, our bosses and coworkers don't get us. But with this group we can laugh, cry and don't have to pretend that everything is fine. They all truly GET IT!"

Fabiana Kleinot

Cushing's disease and adrenal insufficiency patient, member of support group

A Cushing's Collection

There are very few non-medical publications about what a Cushing's patient and their families experience. The Fund self-published my collection of emails sent along my medical journey—providing others with a first-person account of Cushing's disease. Books can be purchased at kickcushings.com



All net proceeds go directly to the Fund

"The Conley Cushing's Disease Fund's donations will help the Pituitary Center at the Hospital of University of Pennsylvania support a ground breaking study of the molecular mechanisms that make Cushing's tumors. We are grateful to the donors of this fund, and hope this research will make a difference in many lives."

Dr. Julia Kharlip

Associate Medical Director,
Penn Pituitary Center; Assistant Professor
of Clinical Medicine

KickCushings.com



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The Conley Cushing's Disease Fund
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The Conley Cushing's Disease Fund is:

- Representative for patient organization for the Pennsylvania Rare Disease Advisory Council, signed into law in July 2018
- A member of Life Sciences Pennsylvania
- A volunteer for the PA Rare Disease Advocacy Network
- A member of Global Genes RARE Foundation Alliance

The Conley Cushing's Disease Fund is a project of The Foundation for Enhancing Communities, fiscal sponsor. The official registration and financial information of The Foundation for Enhancing Communities may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania. 1.800.732.0999. Registration does not imply endorsement.



The Conley Cushing's Disease Fund

TFEC, project fiscal sponsor™

KickCushings.com

The Conley Cushing's Disease Fund est. July 17, 2014, is a project of The Foundation for Enhancing Communities, fiscal sponsor. The funds raised will be used in part to create awareness, support and advocacy for patients and their loved ones who are suffering from this disease as well as support institutions and organizations focused on research and treatment surrounding Cushing's Disease.

**It is estimated that
Cushing's disease
affects 10 to 15 people
per million each year***

What is Cushing's Disease?

Cushing's syndrome is a rare condition that occurs when a person develops a tumor that drives the adrenal glands to make excessive amounts of the hormone cortisol.

Cortisol is a hormone naturally made by the adrenal glands and it is necessary for life. Almost every cell contains receptors for cortisol and so it plays a vital role in every function on which sort of cells it is acting upon.

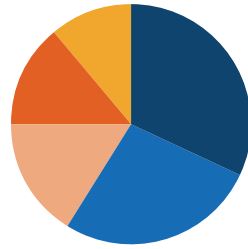
When the ACTH comes from the pituitary gland, it is called Cushing's Disease. Most patients with Cushing's have tumors in their pituitary glands, a tiny organ located deep within the brain structures. Currently in the US, many patients with tumors that cannot be removed are left without effective medical treatment.

Symptoms can include:

- Bone brittleness leading to fractures over time
- Suppressed immune system
- Moon face and buffalo hump
- Recurrent infections
- Fatigue
- Insomnia
- Cognitive difficulties
- New or worsened high blood pressure
- Progressive obesity and skin changes
- Weight gain and fatty tissue deposits around neck and in face
- Thin, fragile skin that bruises easily

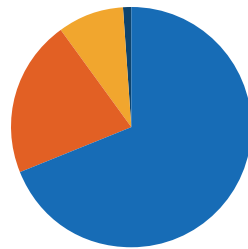
Source:
The Pituitary Society, Society for Endocrinology
& Dr. Julia Kharlip

2014-2017 Budget Review



2014-2017 Expenses

- 32% Advocacy / Awareness | **\$39,385.10**
- 11% Support Group & Outreach | **\$14,481.31**
- 16% Research | **\$20,000.00**
- 27% Operation / Event Costs | **\$33,341.42**
- 14% Medical Professional Educational Outreach | **\$17,195.00**



2014-2017 Revenue

- 69% 2014-2017 Annual Events | **\$182,590.64**
- 1% Miscellaneous | **\$1,514.66**
- 9% In-Kind Contributions | **\$24,413.07**
- 21% Reserve | **\$55,422.00**



2009

While I was diagnosed in 2012, doctors believe I may have had Cushing's Disease as early as 2009.

It takes most people with Cushing's Disease an average of five to ten years to be properly diagnosed.



August 2012

Enjoying time with my son, Carter, Days before my transsphenoidal/ brain surgery at Penn Medicine.



October 2012

After the pituitary surgery failed, I had a bilateral adrenalectomy.



January 2015

Lower right lung resection at Penn Medicine in search of ACTH hormone.



Oct. 2012 - Dec. 2017

Between October 2012 and December 2017, I had over 30 ER visits and hospital stays due to complications from adrenal crisis & diabetes insipidus. In November 2017, I had a total hysterectomy & bilateral salpingo-oophorectomy.

The Conley Cushing's Disease Fund would like to thank our hundreds of supporters, especially:

- Hershey Entertainment & Resorts
- Deon Beverages
- SRA Communications
- Anne Toal Design
- Strongbridge Biopharma