

# Cincinnati Center for Eosinophilic Disorders



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## Bringing us together

Clinic, research, and  
education...

Patients, families, and  
health care professionals...

It's how we're transforming  
a condition into a  
community.

Sean Jameson  
Program Manager

## Welcome to the community

Searching for answers? Searching for support? Welcome to the community.

This is the first issue of EOSearch, a newsletter created by the Cincinnati Center for Eosinophilic Disorders. As eosinophilic disorders are often misunderstood and also on the rise, diagnosis can be a difficult and frustrating process. However, as many of you know, the journey does not end there.

Eosinophilic disorders are chronic conditions, ones for which we do not yet have a cure. These conditions can greatly affect our daily lives, and the search for ways to cope, the latest breakthroughs and people who understand can be a taxing undertaking.

You are not alone. Join our community as we search... for better quality of life, understanding, treatments and a cure.

## What are eosinophilic disorders?

As more and more people become diagnosed with eosinophilic disorders, our community and awareness of these disorders will grow. However, it also means that the question of “What are eosinophilic disorders?” will be asked again and again. This brief explanation will be here to answer that question in every issue of EOSearch. Please spread awareness and understanding of these disorders.

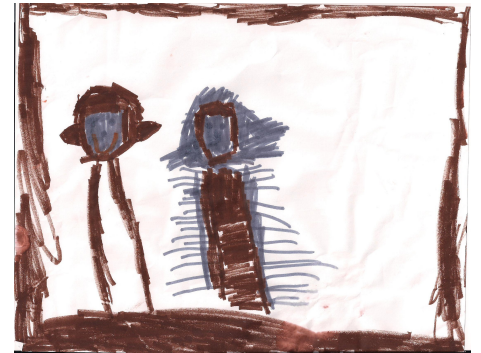
Eosinophils are white blood cells. They are a normal part of our immune system. When triggered by parasitic infection or allergies, eosinophils increase in number and become active, causing tissue inflammation. In the short-term, this inflammatory response is important and effective in

ridding our bodies of intruders.

However, high eosinophil numbers and eosinophil activity also damage our own tissues. Therefore, eosinophils are not meant to be in large numbers or active for long periods of time.

When they are, they cause “eosinophilic disorders”.

Eosinophilic disorders are conditions caused by chronic inflammation, with eosinophils being present in above-normal amounts. The number of eosinophils could be increased in one or several tissues including the blood, and the different eosinophilic disorders are named according to which tissues have increased eosinophils. For instance, eosinophilic esophagitis (EoE) has increased eosinophils in the



Kenny, 5 years of age, drew himself and his brother Larry. Kenny has an eosinophilic disorder.

esophagus and is an eosinophilic gastrointestinal disorder (EGID). EGIDs have increased eosinophils in any segment of the gastrointestinal tract, whereas hypereosinophilic syndrome (HES) has increased eosinophils in the combination of the blood and any organ.

Eosinophilic disorders are chronic conditions, and we are searching together for a cure.



### A few words from our center director

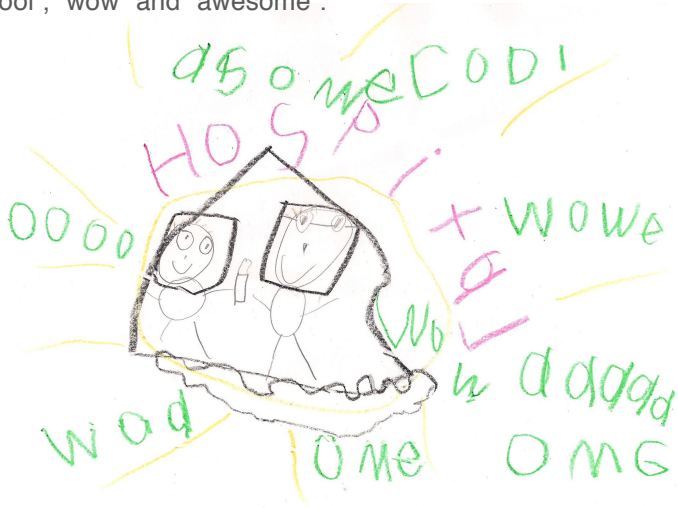
Our mission here at the Cincinnati Center for Eosinophilic Disorders is to provide the best care for every patient, to uncover the reasons and molecular steps involved in eosinophilic disorders, to educate others about these disorders and to find a cure. We aim to learn from each patient and, at the same time, to provide the best care. Thank you for your partnership!

Yours truly,

[Marc Rothenberg](#)

[Director,](#)  
[Cincinnati Center for Eosinophilic Disorders](#)

Larry, 7 years of age, drew himself and his brother Kenny at the hospital. Kenny is holding his bottle with his formula. They are saying cool things like “oh”, “ah”, “whoa”, “cool”, “wow” and “awesome”.



What is involved in clinical research?

Who does what?

## The life of a clinical research project...

*the idea*

Many of you play an important role in improving our understanding of eosinophilic disorders by participating in our research studies. Research projects are a team effort, with everyone having a key role in making it happen. Have you ever wondered what is involved in clinical research or who does what?

The life a clinical research project has many stages. Many steps happen

even before participants enroll and also after participants complete the research study. However, every research project begins with a great idea, observation or question.

For example, a laboratory or physician researcher may want to investigate whether a protein in the blood is higher in patients with or without an eosinophilic disorder or food allergy. At this initial stage, it is important for the

researcher to be thoughtful and thorough in designing the project by clearly stating the question to be tested, how it will be tested and who should be recruited to participate.

Once the project is defined, the researcher enlists the help of a clinical research coordinator (CRC). Learn more about the next part of the process in our December issue.

## Upcoming event

**Cincinnati Walks for Kids:** [Join our team, the Eosinophilic Avengers!](#)

On Saturday October 20th, the Eosinophilic Avengers will join thousands of patients, families and supporters of Cincinnati Children's at Cincinnati Walks for Kids. Our goal is to raise funds to help provide education, support and resources for patients and families facing these disorders worldwide. Past walk events have raised money for many projects, including our specialty camp, Camp CouragEOS.



## What is the role of a physician assistant?



## How we got where we are...

Our professional and personal lives often take some unexpected turns. Looking back, the path from where we were to where we are can be rather surprising.

We often end up somewhere that we had not even considered at the start or perhaps got to where we initially intended but in a roundabout way.

Other times, the path taken is fairly direct and simple.

Join us as we get to know a little more about Jennifer Garrett, physician assistant at the Cincinnati Center for Eosinophilic Disorders, and how she got to where she is.

**Growing up, what were some of your dreams about what you would be?**

Veterinarian, librarian, candy shop owner... ☺

**As you reached independence, what was your career goal?** I had planned on being a veterinarian and majored in biology-chemistry in college to meet the pre-requisites. My father became

quite ill halfway through college. As I watched his providers work, I decided that caring for people was probably a better career choice for me. I worked with a physician assistant during a medical missions trip to Nicaragua when I was a senior in college and felt that it would be a great career choice for me.

**“Physician assistant” is a profession that was proposed and developed in the 1960s, but it does not seem well understood. What are the basic roles of a physician assistant? What training or certification must someone undergo to become one?** Here is the definition of physician assistant as per our national organization: “A physician assistant is a medical professional who works as part of a team with a doctor. A physician assistant is a graduate of an accredited physician assistant educational program who is nationally certified and state-licensed to practice medicine with the supervision of a physician.

“A physician assistant is a medical professional who works as part of a team with a doctor. A physician assistant is a graduate of an accredited physician assistant educational program who is nationally certified and state-licensed to practice medicine with the supervision of a physician.

## Jennifer Garrett

Physician assistants receive training in anatomy, physiology, biochemistry, pharmacology, physical diagnosis, pathophysiology, microbiology, clinical laboratory science, behavioral science and medical ethics and complete more than 2,000 hours of clinical rotations, with an emphasis on primary care in ambulatory clinics, physician offices and acute or long-term care facilities. Rotations include family medicine, internal medicine, obstetrics and gynecology, pediatrics, general surgery, emergency medicine and psychiatry.”

Physician assistants are trained and licensed to make autonomous medical decisions for our patients and are able to collaborate appropriately with our supervising physicians as needed. We must maintain national certification with continuing education as well as by completing the national board examination every 6 years.

**(continued)**

**What initially brought you to the Cincinnati Center for Eosinophilic Disorders?** I have been a physician assistant since 1999 with prior experience in pediatric bone marrow transplant, pediatric oncology, adult gastroenterology and clinical research. I worked at Cincinnati Children's in the past and assisted Dr. Marc Rothenberg with a clinical trial for eosinophilic disorders.

To build long-term relationships with patients and families

**What brought you back to the Cincinnati Center for Eosinophilic Disorders?** My previous position was with adult gastroenterology, and my supervising physician moved the practice further from my home, which extended my commute significantly and limited my time with my family. I was also interested in returning to work in pediatrics and certainly had familiarity with Cincinnati Children's and the Cincinnati Center for Eosinophilic Disorders. I greatly enjoy working with patient populations with chronic diseases as it allows me to build long-term relationships with patients and families.

**What do you enjoy doing in your free time?** I love to read, spend time with my family and continue to try to convince myself that I am a runner. I am starting to train for another half marathon over the winter.

**Looking back, how does your path to here seem to you?** Twisty? I think the career of a physician assistant is a great one as it allows us to cross between disciplines and continuously add to our skill set. I am excited to be back at Cincinnati Children's to assist the members of the Cincinnati Center for Eosinophilic Disorders in continuing to improve care for our patients!

## Reaching out to you and each other

We understand the ever-growing importance of websites and social media in our daily lives, both personally and professionally. These outlets give us a chance to connect to each other even if there is a lot of distance between us. Do you follow us on the internet? Our center and the Rothenberg research laboratory maintain Cincinnati Children's webpages and Facebook pages. We also tweet. Come visit us and find each other.

### Webpages:

[www.cincinnatichildrens.org/cced](http://www.cincinnatichildrens.org/cced)

[www.cincinnatichildrens.org/rothenberg](http://www.cincinnatichildrens.org/rothenberg)

### Facebook pages:

[www.facebook.com/CCEDeos](http://www.facebook.com/CCEDeos)

[www.facebook.com/RothenbergEosinophilicLab](http://www.facebook.com/RothenbergEosinophilicLab)

### Twitter:

[twitter.com/eosinophils](http://twitter.com/eosinophils)

[twitter.com/RothenbergLab](http://twitter.com/RothenbergLab)



Sean

## Parent perspective... *going to school*

One of the things that can increase anxiety in a parent of a child with an eosinophilic gastrointestinal disorder (EGID) is the thought of their child going off to school. In addition to the anxieties that parents of healthy children have, parents of a child with EGID must also contend with anxiety in finding a balance between keeping the school environment safe and still making it fun and the least restrictive as possible. While there are many schooling options to choose from (public, private, home-school, online), we will be sharing our background and perspective from our experience in public and private schools. We have found that there are many commonalities between both of these options when it comes to providing a safe environment for our children to learn and thrive.

Over the years, there are many things we have learned that have helped to build a successful relationship with our children's schools. Of these, the most important is building a solid relationship with the teacher. We begin each school year by discussing background information about the disease and going over plans for accommodations. We

also have the crucial discussion about the three-way partnership that occurs between the child, the parent and the teacher. Each person plays a vital role in the success of the child at school, and therefore, each person has their own responsibilities. It is very important to clearly outline the expectations of each person upfront in order to minimize confusion later. We feel strongly about including the child in this partnership because it begins to teach them how to advocate for themselves, thus preparing them for managing their disease in adulthood. Having the child engaged early will help ease the transition later in life.

Here are some other tips that we have found to be successful:

**You get the same energy out of the interactions as you put into it:** We have found that entering meetings with a positive attitude operating on the assumption that the safety and well-being of the child is the top priority of everyone involved has led to more successful outcomes for everyone involved.

**Time is precious to everyone:** Teachers are stretched thin. And though they want the best for our children, we have to respect the fact that our child is not the only child that



a teacher is managing during the day. Thanking them for their efforts goes a long way!

**Communication is key:** In discussions with teachers, determine the most efficient way to convey information and updates to each other. Depending on the teacher, this may be via email, a weekly folder or notebook, daily checklist, phone calls, or another system the teacher may already have in place. We have found that being flexible in communication methods has helped tremendously.

**When things go wrong:** We have learned from Peter Wright of Wrightslaw, a special needs school advocacy organization, one very important thing. When something does not go according to plan, it is

**(continued)**

best to do nothing for 24 hours. This allows time to calm emotions and for you as the parent to then have a more productive conversation with the school staff to prevent the issue from occurring again in the future.

Whatever school option you choose for your family, we wish you much success in the upcoming school year!

Sincerely,

[Cathy Reidy & Melissa Scott](#)

Co-Presidents

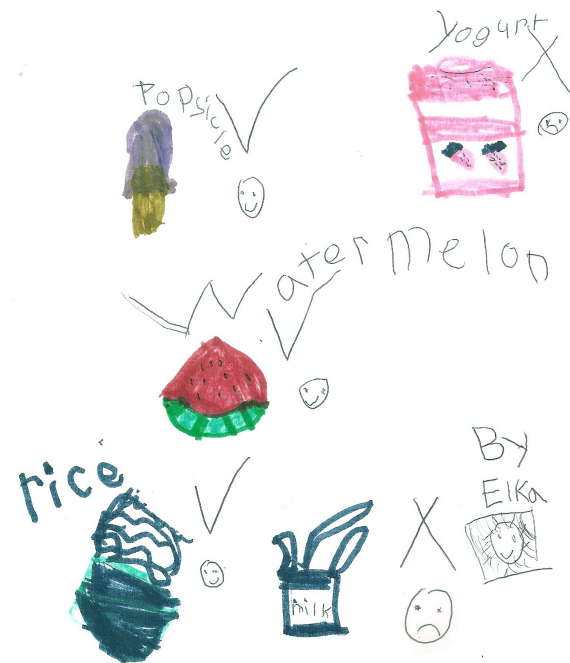
[Cincinnati Eosinophilic Family Coalition](#)

Set the tone with positive energy

Acknowledge and respect others' time

Establish effective systems to communicate

Give yourself 24 hours to reflect when things go wrong



Elka, 6 years of age, is a young girl with a love of art, as shown above (left) by her reproduction of Vincent van Gogh's "Starry Night". She also has eosinophilic gastrointestinal disorders (EGID), both eosinophilic esophagitis and eosinophilic gastritis. Another of her drawings (above right) shows how she views her "EGID reality".

*"Drawing has been so therapeutic for Elka (and it probably is for others with this disease). After she was released from her weeklong hospital stay, she came home and immediately started drawing, sometimes for hours on end. She drew happy pictures, and also pictures of her stay in the hospital, which were quite sad."* – Elka's mother

## Tips for reading a scientific article

What sparks your interest in reading an article? How can you determine its scientific merit? Below we offer a few tips and reminders that we find useful when tackling a scientific article.

First, have an expectation of what you want to gain from reading the article. This helps your analysis and keeps you interested in the material presented.

Second, know where to expect certain types of information. Like sewing or cooking, scientific articles typically follow a pattern or a recipe. Unraveling each part of an article provides specific insights related to the topic under study.

Third, keep in mind the basic steps of the scientific method: define a question, gather information and resources (observe), form a possible explanation (hypothesis), test the explanation by performing an experiment and collecting data in a reproducible manner, analyze the data, interpret the data and draw conclusions that serve as a starting point for new questions and explanations and report results. This method is the general procedure for all evidence-based research.

Although the specific parts of an article can depend on the journal in which it is published, the following outlines the typical parts of an article and what purpose each part serves for the reader.

**Title:** A well-written title should be easy to understand, help clarify your expectations and should summarize the work of the article. However, some titles may be difficult to understand until you know more about the specific molecules or concepts being tested. When in doubt, consult the abstract.

Have an expectation of what you want to gain from reading the article

Know where to expect certain types of information

Keep in mind the basic steps of the scientific method

**Abstract:** The abstract provides a brief overview of what the article is about. It should explain why the authors did the study, how they did it, and what their findings were. Sometimes abstracts have subheadings corresponding to the main sections of the paper (e.g. objective, methods, results, conclusion), called a “structured” abstract; other abstracts do not have subheadings and are called “unstructured”. The format of the abstract is dictated by the journal and does not reflect the organizational abilities of the authors or the scientific merit of the article. The content of the abstract does. An abstract should be a bare-bones summary of the article and can help you decide whether or not to read the article.

**Introduction (The “why”):** The introduction provides an understanding of the authors’ motivation for conducting the research and the significance of the research for others or the field of science. It should explain why the research was done, important prior research, concepts related to the study and the objectives and hypothesis of the article.

(continued)



**Methods (The “how”):** The methods provide details on how the research was set up and carried out. More detailed methods can help the reader determine whether the article is relevant to your expectations and help other researchers repeat the experiments.

**Results (The “what”):** Results are statements of what was observed, the data. The data are often also presented in tables, illustrations or figures.

**Tables, illustrations and figures (The “what”):** Tables organize data in one place for easier reading and comparing of groups. Figures and illustrations often present the data in a more compact and intuitive way. Understanding tables, illustrations and figures is extremely important in understanding a scientific article. It can involve a lot of page flipping, going back and forth between the written statements in the results section and the corresponding table, illustration or figure.

**Discussion (The “interpretation”):** This section is intended to “connect-the-dots” by explaining what the data mean and why these data support or overturn the study’s hypothesis and objectives. Here the authors examine and interpret the data to draw conclusions. Some authors also use this section to explain how the data fit into or overturn current theories in the larger field of study.

Fourth, decide whether you agree with the authors’ methods and interpretations. Did the authors choose the best method to test the question? Do your own conclusions about the data agree with the authors’ analysis?

Fifth, look for other opinions. Any subsequent related commentary or editorials could provide additional insights related to the original article.



Carol

Decide whether you agree with the authors’ methods and interpretation



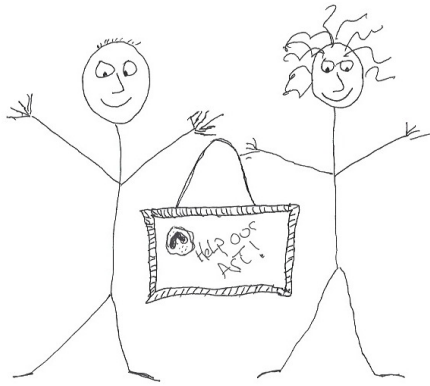
Shawna

Look for other opinions

## Upcoming event

### First Annual CURED EGID Conference at Cincinnati Children’s:

On Friday November 2nd and Saturday November 3rd, our center and Cincinnati Children’s will be hosting the First Annual CURED EGID Research Symposium. Our goal is to share and gain knowledge in the emerging field of eosinophilic gastrointestinal disorders. This two-day conference is for physicians, scientists, nurses, social workers, medical care and research team members, patients and families. Participants will gain knowledge about the diagnosis, therapy, psychosocial and social aspects and science of eosinophilic disorders. Friday features research presentations and an evening fundraising event, and Saturday is a family conference. Contact [cced@cchmc.org](mailto:cced@cchmc.org) for information.



## Send us your art!

Our community is gearing up for its next newsletter. Although our editor-in-chiefs (pictured to the left) draw some mean stick figures, we would rather have yours!

For each of our newsletters, we would like to highlight a drawing or picture by a child or adult (or a family member of a child or adult) with an eosinophilic disorder.

Ready to make some art? Go for it! Email your art to [cced@cchmc.org](mailto:cced@cchmc.org).

## Newsletter Contributors

Thank you to everyone who contributed formally or informally to our very first issue of EOSearch, newsletter of the Cincinnati Center for Eosinophilic Disorders, with a very special thank you to those who contributed their art, words, and thoughts. You inspire us and bring us together.

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### This issue's Contributing Artists:

Elka (age 6)  
Kenny (age 5)  
Larry (age 7)

### This issue's Contributing Authors:

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*Shawna Hottinger*

A few words from our center director  
*Marc Rothenberg*

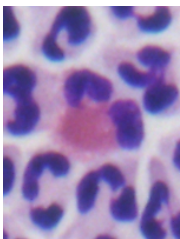
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*Cathy Reidy, Melissa Scott*

Tips for reading a scientific article  
*Carol Henderson, Shawna Hottinger*

Other EOSearch content  
*Shawna Hottinger, Sean Jameson*



## Give Today

We truly need and appreciate generous donations to support our research aimed to improve patient outcomes at the Cincinnati Center for Eosinophilic Disorders. To donate, please visit our [donations page](#) or [www.cincinnatichildrens.org/cced](http://www.cincinnatichildrens.org/cced) or contact Marc Rothenberg at [marc.rothenberg@cchmc.org](mailto:marc.rothenberg@cchmc.org).