

# YouthACT Team Profile



## YouthACT Seize Control

**Youth:** Blair Hagelgans and Erin Seiler

**Adult Partner:** Elizabeth Beil

**Supporting Organization Contact:** Allison McCartin

**Supporting Organization:** Epilepsy Foundation Eastern Pennsylvania (EFEPA)

### Introductions

#### Youth

My name is Blair Hagelgans, and I am a junior at York College of Pennsylvania, majoring in Public Relations and minoring in Nonprofit Management. I work with several nonprofit organizations and want to get a job in individual fundraising when I graduate. I am also planning to potentially go to graduate school for Nonprofit Management in the near future. I am on the Youth Council for the Epilepsy Foundation of Eastern PA, in addition to serving on YouthACT.

My name is Erin Seiler, and I am a junior at Cabrini University, majoring in English with a concentration in Creative Writing. I have been and continue to be a dedicated advocate for youth with disabilities. I am involved in the Youth Council for the Epilepsy Foundation of Eastern Pennsylvania (EFEPA), as well as a camp that the Foundation runs for children with epilepsy. I am also a part of Delta Alpha Pi, a disabilities honors society. Through YouthACT, I hope to advocate for and encourage youth to speak up and have their voices heard.

#### Adult Partner

My name is Elizabeth Beil, and I am the Camp, Transitions and Hispanic Services Coordinator for the Epilepsy Foundation Eastern Pennsylvania (EFEPA). Since joining the EFEPA team in May 2015, I have worked to promote a strong epilepsy community through Camp Achieve, diverse programming for transition age youth and young adults, and the initiation of programs to involve the Hispanic communities throughout the Foundation's service area. I earned my Bachelor's degree in Psychology from Bryn Mawr College in 2001. Prior to joining the EFEPA, I engaged in a variety of professional experiences including managing residential services for developmentally disabled adults, coordinating healthcare services for underprivileged Guatemalan girls, and spending 10 years in Guatemala building a K-12 school and supporting community education and infrastructure projects. I have been drawn to work with youth with disabilities and chronic illnesses through my professional as well as personal experiences.

I was drawn to participate in YouthACT by the opportunity to network across disabilities, regions, and systems. I hope that the work of YouthACT Seize Control shows youth that they have an important voice and that there are adults who are listening. Looking ahead, I see the YouthACT program leading to improved integration of youth voice within the EFEPA's vision and programming. On a larger scale, I see YouthACT working to improve transition planning and implementation across the systems of education, employment, healthcare, and transportation to support the potential of individuals with a wide range of disabilities.

# YouthACT Team Profile



## Supporting Organization Contact

My name is Allison McCartin, and I am currently the President and CEO of the Epilepsy Foundation Eastern PA (EFEPA). I began my work with the Foundation in November 2007 in the Development Department, planning the numerous fundraisers that fund the EFEPA's free programs and services. Through the relationships I built in the Development Department, I was asked to assume the role of President and CEO by the Foundation's Board of Directors in February 2010. I graduated from Dickinson College as an International Business and Management Major aspiring to work in the nonprofit sector. I am challenged each day by the mission of EFEPA to bring awareness and understanding to the cause.

My goal for YouthACT participation is to give youth with epilepsy an opportunity to represent the cause and their beliefs on a national level in hopes of creating strong spokespeople for the Foundation. Through the leadership experience they receive, I hope to develop advocates on the local level that can speak to support groups run by the Foundation or at the Camp Achieve program. My long-term goal is that the transition services provided to youth and young adults with epilepsy become more transparent and consistent across the nation.

## Supporting Organization

YouthACT Seize Control is supported by the Epilepsy Foundation Eastern Pennsylvania (EFEPA). As an independent affiliate of the Epilepsy Foundation of America, our mission is to stop seizures and SUDEP (sudden unexpected death in epilepsy), find a cure, and overcome the challenges created by epilepsy through efforts including education, advocacy, and research to accelerate ideas into therapies. EFEPA works to fulfill its mission by focusing on education, support, and advocacy. We offer a range of free services and programs to improve the quality of life and empower those who are affected by epilepsy and their caregivers. Key programs include but are not limited to Community Education & Outreach, Epilepsy Educational Conferences & Workshops, Seizure Trainings, Recognition Programs, Legal & Medical Referrals, Children & Family Services, Adult Resource Services, Young Adult Initiative, and Camp Achieve.

Our programs focus on encouraging individuals with epilepsy to take ownership of their diagnosis and self-advocate throughout their lifespan. We feel that our adolescent and young adult constituents are at a critical time in this process. They can provide insights into the social-emotional and educational-vocational experiences of the transition process, which is a focus of the YouthACT program. We aim to improve the ways in which we provide support to youth through legislation and program development. Through collaboration with young adults, our organization is engaging in capacity building for the future leaders of our community and influencing measurable improvements in the supports provided to transition-age individuals with epilepsy and other disabilities at both the state and national level.

## Activities

We assisted with a REACH (Rapport, Empowerment, Advocacy, through Connections and Health) workshop for youth with epilepsy and their parents. The REACH program was sponsored by EFEPA and the Children's Hospital of Philadelphia. This one-day workshop had speakers on health care transition, vocational training programs, and breakout sessions for youth and adults to discuss transition challenges. We led icebreakers and discussion for the breakout sessions. We also presented on the YouthACT model and invited attendees to join the peer network.

# YouthACT Team Profile



Our team also had the opportunity to present at two conferences: the Institute for Educational Leadership (IEL)'s Family and Community Engagement Conference and the Pennsylvania Community on Transition Conference. Presenting at these professional conferences gave our team the chance to get the word out about who we are and what we are working on. It was an amazing opportunity to connect with people who had experience in the fields where we are trying to make an impact. We were able to learn so much about new programs, already existing programs, and important events that were occurring in the world of disabilities. Because of the connections made at the IEL conference, we were invited to participate on a "Been There, Done That" panel at the PA Community on Transition Conference, in addition to the YouthACT workshop. We not only got to improve our presentation delivery skills, but we enjoyed the process of designing the presentation as a team.

The Covers for Comfort campaign was another activity we started as a way to support kids and youth undergoing neurosurgery or long-term epilepsy monitoring. We know personally what it is like to have long hospital stays, which can be scary and isolating. The blankets are a small token to help kids know there are others out there who understand their struggles. Blankets were made by members of the peer network and by local Boy Scout Troops. The group has donated 20 blankets to the Children's Hospital of Philadelphia to date. The goal is to donate at least 100 blankets. Included with each blanket is a short introduction to the project by Blair and links to learn more about epilepsy and the YouthACT program.

## Peer Network

Our peer network for YouthACT Seize Control includes about twenty members with varying degrees of involvement. We draw the majority of members from the Youth Council of the Epilepsy Foundation of Eastern PA. Until recently the members were mostly ages 18-25; however, the team leaders and current network have been reaching out to younger groups because there is interest from high school and middle school students. Team members are from Montgomery, Delaware, Bucks, Philadelphia, and Chester counties in Pennsylvania, as well as one member from New Jersey and one from New York.

Our members have presented at EFEP youth functions, support groups, and Camp Achieve to encourage youth to pursue leadership opportunities including those provided by YouthACT. Our peer network provides insight into the interests and abilities of the members to help identify ways Seize Control can accomplish the team action plan. For example, our peer network members have raised concerns with the current videos available on epilepsy that are meant for youth and young adult audiences. Our team has been encouraged to consider making a video for youth by youth that can provide appropriate education that is accessible to a range of ages.

## Tips

To all the youth out there, be confident in your ideas and your thoughts. Your voice doesn't need to be the loudest or most eloquent. "Voice" can mean many different things. You may feel more comfortable writing or drawing to express yourself. It's also important to remember that your perspective is just as important as any adult's perspective and so many adults want to know what you're thinking!

# YouthACT Team Profile



We advise that youth and adults should respect each other's views, ideas, and perspectives in order to work together as partners. It's important for all voices to be heard. Just because one person is older doesn't mean their view is worth more. Just because a group focuses on youth, doesn't mean that adult perspective should be discounted. It's a balancing act that can look deceptively easy but requires patience and hard work by a dedicated group.

## TIPS FOR DEVELOPING A PEER NETWORK

For other youth who want to develop a peer network, we recommend that you dream big and jump in! Here are some ideas:

- Spread the word on what you're passionate about changing.
- Use all the resources you have such as social media, search engines (Google, Bing, Yahoo, etc.), and the people you know. Think about where you and the people you've connected with can meet (a park, a school, a restaurant, etc.) or talk (via phone, Skype, Facetime, etc.).
- Set a time and date that best works for you and your team.
- Don't be afraid to start out small and don't be afraid to fail! Learning from your failures is the key into building your dream into a reality.

When you need advice, go to people that support you, respect you, and inspire you. For YouthACT Seize Control, that list includes family, friends, teachers, medical professionals, and business leaders. It can be helpful to approach people with differing views and life experiences to help challenge you to strengthen your opinions and directions. But make sure you have a core group that always has your back when you need support!

## Reflection

Opportunities like YouthACT are important because they give youth a chance to have a say in creating and modifying programs that greatly affect their lives and the lives of countless other youth in the nation facing similar problems. Our initiative recognizes, respects, and empowers youth to speak up, have their voice heard, and make a difference. Erin says, "YouthACT provides an outlet for young people to foster leadership skills, to find their passion, and to serve the community through advocacy and outreach."

Our team has learned a lot about ourselves by being involved in YouthACT. Erin says, "I have learned that confidence and not being afraid to fail are the two biggest keys to success. I learned that you never know who you'll meet and that networking is so important. Most of all, however, I have learned that youth do truly have the power to make a difference in both their lives and lives of those around them." Elizabeth has learned about other peer groups and teams from YouthACT and how to reach other groups through networking and seeing what is possible for herself and her team through their hard work.

# YouthACT Team Profile



Our adult partner, Elizabeth, has been working to promote youth voice by providing opportunities for our youth to network with leaders of the Epilepsy Foundation Eastern PA. Hearing from this important constituent base has helped staff and board members consider how the Foundation can ensure programming reflects the diverse needs of our community. We implemented a Young Adult Weekend Retreat this past year that focused on overall wellness through yoga, dance movement therapy, art therapy, health care advocacy, and vocational exploration. Because of the enthusiasm of the youth within our peer network, we invited young adults to be involved in the annual Epilepsy Foundations of Pennsylvania's Legislative Breakfast and Share your Story workshop in Harrisburg, PA. It was rewarding to see the impact the youth had on each other, the adult participants, and the legislators with whom they interacted.

## Looking Forward

Our goal is that YouthACT is a springboard for continued integration of youth within the fabric of the Epilepsy Foundation Eastern PA. Elizabeth says, "I believe that the cross-disability and cross-system work our team has been exposed to will continue to influence my choices as I continue in my professional development. I will continue to draw upon strong youth, young adult, and adult leaders who can inspire youth with epilepsy and other disabilities to find their unique, beautiful voice and share it with their communities."

Erin shares, "YouthACT has, in many ways, been a jolt of inspiration to me. Through everything I've learned and the connections I've made, I've gained so much confidence in my ability to make a difference. YouthACT has given me a set of tools, and I want to utilize them to make a difference I never thought I could. Since joining YouthACT, I have learned just how much of an impact youth can truly make. I gained the confidence to speak and present in front of large groups of people. Networking has become almost second nature to me. I will continue to use and improve these skills as I advance in both my professional and personal life."

In the future, Elizabeth wants to continue to work with YouthACT in any way she can. As a team, Seize Control hopes to continue creating their own projects and presentations. They also want to work with other YouthACT teams to learn and help where they can. They value the work the other teams have been doing.

The EFEPa will continue to support youth and young adult programming through the Youth Council, Camp Achieve, Young Adult Retreat, and other educational programs. These programs focus on the development of strong community bonds through mentorship, advocacy, leadership development, and fun. The Foundation will continue to seek out opportunities to allow youth to design and implement social activities, educational programs, and awareness events.