COOPER • MEGHAN • LAUREN
GRACE • VALERIA • MITALI
ABBY • JANA • SAMUEL
VALENTINA • ELLA • SIMONE
OLIVIA • KALEE • MEREKI

REFLECTIONS ON PEDIATRIC CLINICAL RESEARCH

Submissions to the ICAN/DCRI Anthology Project

OLIVIA • KALEE • MEREKI
VALENTINA • ELLA • SIMONE
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ICAN
International Children's Advisory Network

Duke Clinical Research Institute | FROM THOUGHT LEADERSHIP TO CLINICAL PRACTICE

COOPER

age 18

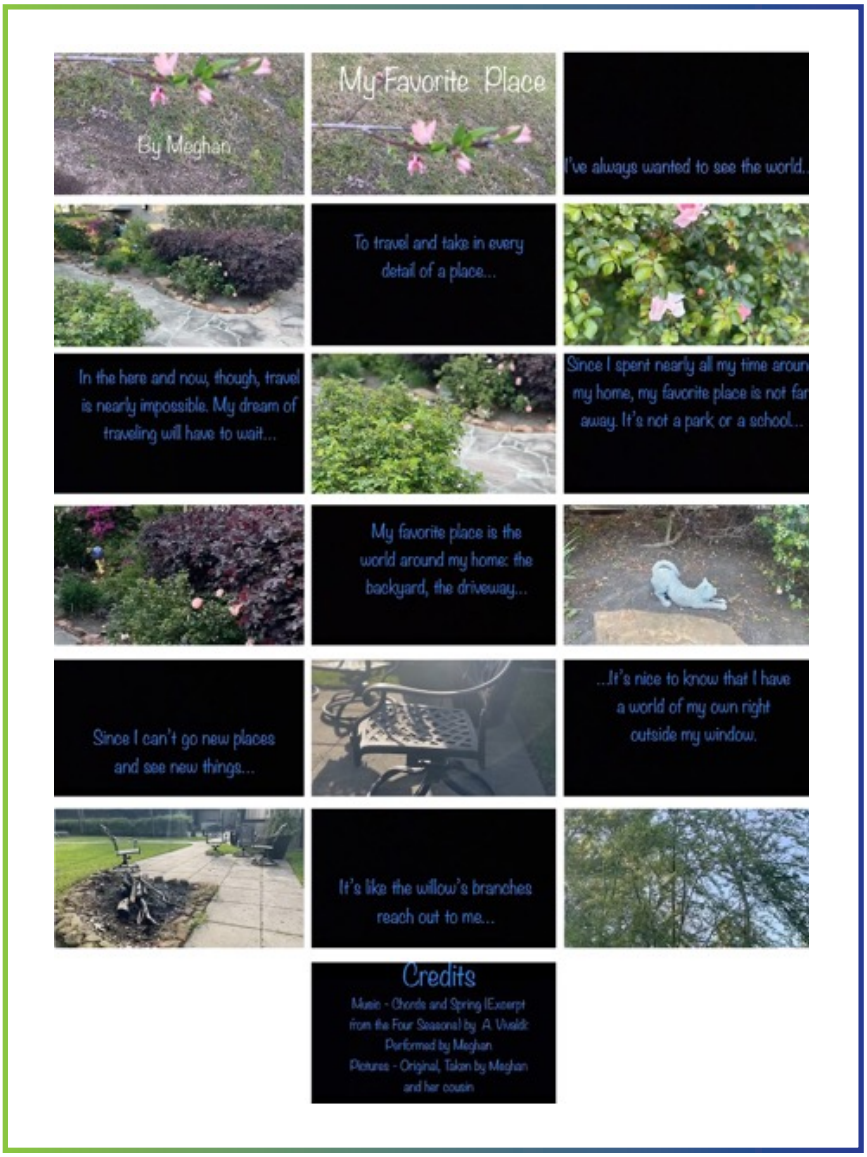
Cooper is a high school senior with a keen interest in engineering, science, mathematics, and especially medicine. Growing up with a mom that works in the field of pediatric clinical research, Cooper understood the challenges that children and young people often face when diagnosed with rare and complicated medical conditions. Using this insight, his expression of hope for patients is displayed in his artful jewelry design. The stone identifies the child while the sterling silver overlay is a reflection of the care of scientists, doctors, researchers, and family. Cooper's design shows the deep strength and gentle support of the patient as they pursue treatments for not just themselves, but all children around the world.

MEGHAN

age 12

Meghan is a young girl that lives with multiple rare medical conditions. Meghan enjoys participating in opportunities within pediatric clinical research that allow her to share her experience and expertise with other young people. Adding the complicating factor of the global pandemic, in order to stay healthy, Meghan has shared that she must stay home to avoid COVID-19. To inspire other children that may also be home-bound, Meghan shares an inside look to her favorite place in the world - her own magical backyard.

VIDEO

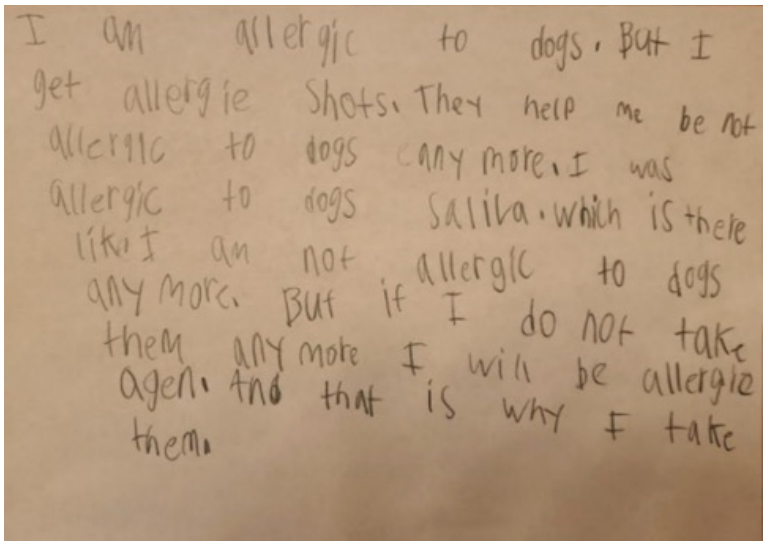


LAUREN

age 7

Lauren is a 7-year-old girl that has been diagnosed with serious allergies. One allergy is specific to her beloved family dog. Lauren is currently receiving medical treatment and in her own words, shares the following description:

"I am allergic to dogs. But I get allergy shots. They help me be not allergic to dogs anymore. I was allergic to dog's saliva which is their lick. I am not allergic to dogs anymore. But if I do not take them (allergy shots), I will be allergic again. And that is why I take them."



GRACE

age 11

Grace is an 11-year-old girl who was born at just 32 weeks. As an infant, Grace spent a month and a half in the NICU. Her drawing represents her neonatal time of life, in which the medical care and treatment at the NICU helped to save her life. Today, Grace enjoys participating in sharing her voice and helping to support her community of doctors and researchers, and also families and babies through her artistic drawings. Grace hopes everyone can be inspired to help others.

VALERIA

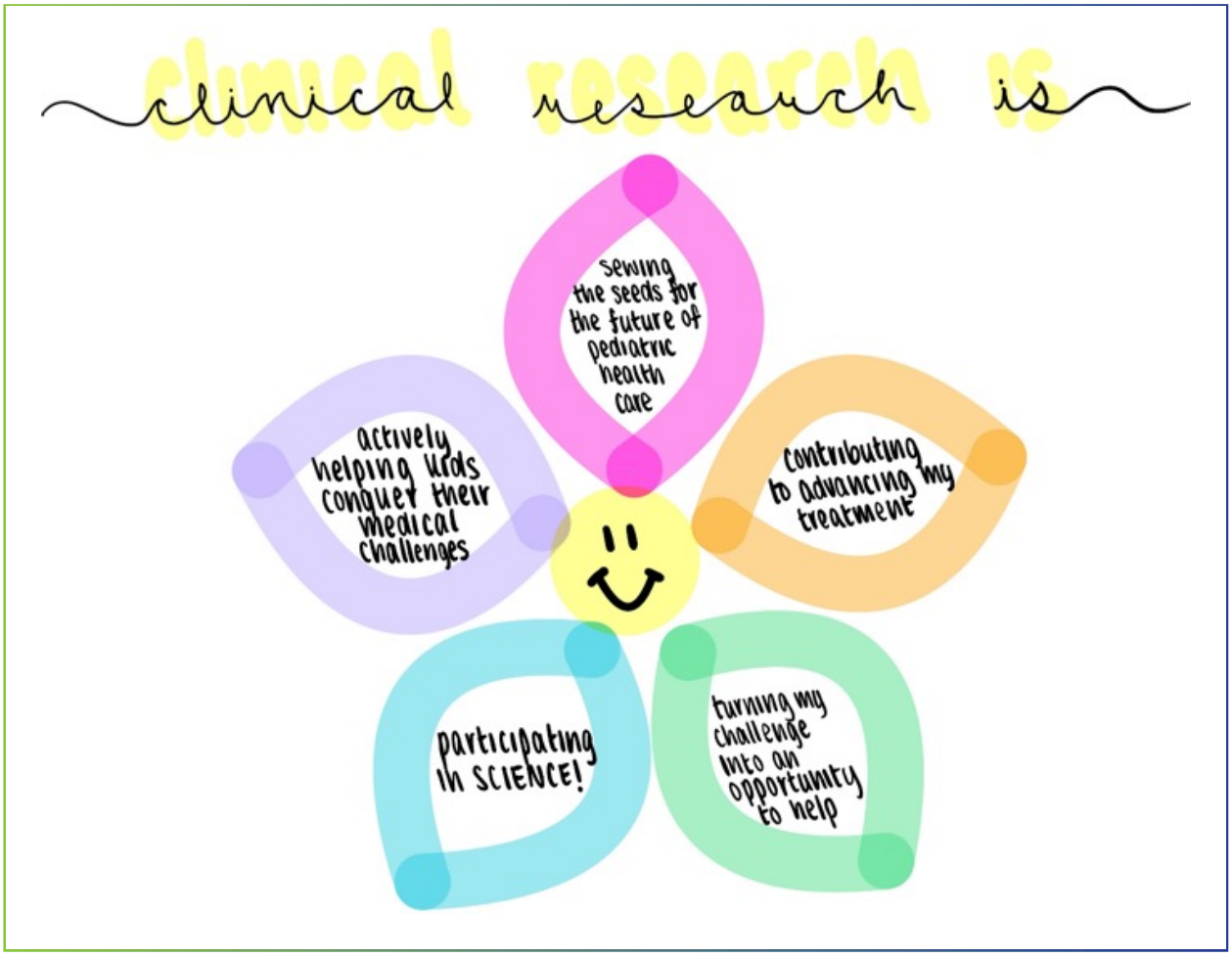
age 17

Throughout her childhood, Valeria has participated in many clinical research trials. Valeria has a first-hand understanding of what it means to be a young patient and hopes that by sharing her experiences, other kids will be able to learn from her. Valeria's own goal is to make clinical research trials accessible to all kids from anywhere.

MITALI

age 19

Mitali has been a big supporter of kids living with medical conditions her entire life. One day, Mitali hopes to support all kids as a pediatrician. As a future doctor, Mitali will focus on the needs of the whole patient to ensure that kids are both mentally and physically healthy.



ABBY

age 16

Abby is a high schooler with a keen interest in medicine. Always wanting to be a doctor, Abby has a strong focus in understanding new ways of helping to support pediatric clinical trials. Abby cares deeply about the world around her and hopes to be able to one day create new medical innovations so that kids can receive the cures that they deserve.

ESSAY

Research Essay

Research is a concept with such a broad meaning, yet I've spent years trying to pinpoint a definition for it. However, research never has one correct answer, nor is the answer ever permanent. Our world is continuously changing, and research aligns with the change. The explanations about cancer 100 years ago are not the same today. Moreover, 100 years from now, the information will not be identical. Although this may seem like a straightforward understanding, it was something that took me years to accept and learn that it is ok not to have the answers instantly.

In second grade, I first interacted with the term "research" in a library. We were given our first assignment to investigate a question on the school's new iPads. The question presented was simple with a direct answer to follow; my question was, "what year did Nebraska become a State?" I quickly typed the question into the Safari browser, with a couple of mistypes, and received the answer "1867". There were no follow-up questions like why Nebraska became a State or its founders. This forthright approach made me relate research to math—one answer to the problem. However, research is not like a math problem with exactly one solution, and every other choice is incorrect; research is a never-ending question with multiple answers to support it. Nevertheless, in second grade, my brain was not pushed to learn an in-depth understanding of the topic; therefore, this realization didn't click. Soon after, I encountered another research project in middle school. We were instructed to research an endangered animal and learn why they were threatened along with simple facts about the animal. Although this project extended my research knowledge, I still did not comprehend that research is not a one-answer street. Research is about exploring a specific topic and acquiring knowledge about the issue in all different dimensions, so you are well informed while still being open to adding new information in the upcoming years. Further, my first years in high school broadened my perspective on the research concept. It started, with, once again, a research project. This time, my task was centered on how genes define us. I found several books, websites, and articles that would help me navigate this project. But as I was gathering information, I was instantly overwhelmed with the knowledge thrown at me. I would read a paragraph and write down the answer to my research project and

move on to read the second paragraph, revealing a new solution. I was so confused and startled that all of this information could relate to one topic. Furthermore, some of the data has not even been discovered yet! I felt like I was swimming in a pool of information, trying to find the correct answer to the research question. That is when I acknowledged that research is not simple. Research is not supposed to be an easy-to-find question but more like finding a needle in a haystack. Research cannot be completed in one day; it is over a long time because you are slowly collecting data. Similarly, it entailed understanding the connection of points in the research, reasons why this information could be critical, and solutions to improve a situation or treatment.

Lastly, understanding the behind-the-scenes of research in the medical field is critical. Doctors, professors, and scientists are constantly discovering new answers to unknown questions about diseases so they can develop treatments to help their patients. When you go into the situation with an open mind and realize it may take weeks, months, and years to find the solution, it will benefit you. In addition, you will be able to communicate more clearly and effectively with your patients. If one of your patients has a rare or unknown disease, you need to be able to communicate with your patient that there are not many details linked with your illness and that research is going on to find answers. The patient may not understand why the doctor does not have answers and will feel frustrated. As a doctor, you need to know where they are coming from and explain that research takes time and the answers will be known, but in an unknown time frame.

All in all, researching a topic is not finding one solution like a math problem. It is not like an English assignment where you read and write a summary of what you comprehend; it is a different type of learning - one that takes time and patience to understand that you will never know every single fact about the subject. It is more about falling in love with the process of learning the subject, comprehending the information you just read, creating solutions to help improve methods/situations, teaching the information you discovered to your community, and consistently gaining knowledge on the topic every day!

JANA

age 17

Jana is a creative young person that views the world through her own canvas and paintbrush. Jana believes that it is important to support all patients, especially children and young people, with the best innovation, medicine, treatments, and care available. In her own words, Jana explains:

"The painting aims to express the Light and Hope that comes from clinical research. On the left, a researcher is painted in a dark background which represents the disease and the unknown. On the right, the colors become lighter and brighter, and there is a family with their child, full of happiness and hope because of the new effective and safe treatments. Mountains symbolize the state of a long and healthy life."

SAMUEL

age 21

Samuel serves as a volunteer Teen Advisory Board member at his local hospital. Samuel understands that sharing his story, while very personal, is extremely important to helping other young people (and their families) to not feel so alone.

In his own words, Samuel shares,

"As an Acute Lymphoblastic Leukemia survivor, I want to encourage others going through similar experiences while advocating for pediatric clinical research centered around family therapy. More and more research reveals the tremendous psychosocial damage oncological issues in children have on parents. My poem fights to demonstrate how relevant and urgent this type of research is."

Mom and Dad, by Samuel

Flower in a vase
Filled with murky water
Sits in solitude
By the bed of
Sorrow.

Gardens watered
By the tears of my mother.
Grass grown
By the work of my father.
Sorrow.

A flower intoxicated
By the medicine of a shaman
Infected by his own body
Cells against cells.
Sorrow.

A father drives silently on
I-49
After work, his eyes
Become thunderclouds above the rose garden.
Sorrow.

A mother cooks
For someone who cannot eat
And someone who does not sleep
But cooks to fill her heart that was emptied by
Sorrow.

But the boy sat in his hospital bed, watching the gardeners at work. Their sorrow was his hope. Their tears, his work. He worked like a sacrificial lamb, because their love made him strong. A single tulip in a wasteland. A bountiful harvest after a laborious sow. A young, bright sun to mom and dad.

VALENTINA

age 17

Valentina is passionate about science, medicine, and research. In her own words, Valentina explains her art and why it is especially important to support clinical research.

"Clinical research involving children is essential to determine treatments that could work better and be safer for them. Seventy percent of medicines that are given to children have been tested only on adults. If clinical trials with children are not conducted, then the treatments used for adults are applied also to children, not knowing the effect that this could have on them. Children's bodies are different and consequently, they can have different immune responses. If clinical trials cannot be led directly with and for children, these differences cannot be detected and so the researchers cannot modify the treatments to make them more efficient and less risky for children. To be accurate, a clinical trial needs a sufficient number of patients, so it is of vital importance that more children with childhood conditions make themselves available for pediatric research. As well as being helpful for future generations and for other children in the same situation, taking part in a clinical study can be an opportunity to have access to something not available yet but potentially better than the medicines regularly used. If scientists and researchers decide to test a new treatment, they must have strong reasons to believe that it might work better than the standard of care."

ELLA

age 16

Ella is a high school student that enjoys her family, friends, horses, and a love of science. Through her essay, Ella dives into better understanding of clinical research and shares her thoughts of why it is important to kids (and families) everywhere.

ESSAY

Knowledge Is a Book in Progress - Research is the Author

"Czy mówisz po polsku?", she asked when I had just finished untacking my horse. "Tak, mówię po polsku", I responded.

During my horseback riding lesson I noticed that my fellow horseback rider was speaking Polish to her husband. I made a note of it, being Polish myself, and went up to her after the lesson to say hello. The fellow horseback rider turned out to be an accomplished Polish researcher working at a prestigious university lab in my hometown. Fast forward a few months, and I ended up spending the summer before my junior year of high school helping her at the lab. It was my first, at the time, recognized exposure to research. I assisted in research on gene regulatory networks that influence cardiac embryonic development; a segment of science in which there is a lot to wonder and want to know about. I spent my days running PCR's, loading gels, isolating RNA, running ECGs on mice, clipping and tagging mice, dissecting mice for tissue samples, and trying to understand complex biological terms. I learned, partly because I returned to assist at the lab during the school year, that research takes time, and because research is driven by the mystery and art of human life, it is often pursued diligently, over years.

As I said, working at the lab was my first recognized exposure to research, but research is done at all stages of one's life. Research, in its basic form, is human nature. Research is acting upon curiosities to learn more about life's wonders. Curiosity manifests itself in people of all ages in many different disciplines. Curiosities motivate and fuel research, whether that research be conducted on the playground by a child, at school by a student, or at a lab by a professional.

What is more beautiful and confusing than life and the truth? Pursuing, questioning, and investigating life and truth, researching, is something that people do. Poets, artists, teachers, priests, and researchers all pursue the understanding of life and the truth in their own respective ways. A sculptor has a stone and chisel; researchers have a laboratory and equipment. There is a shared beauty in both sculptures and science.

I have never conducted pediatric clinical research. My work at the lab is bench work research, a cousin of clinical research. But my experiences have taught me that research takes time, and to get to a point where pediatric research is clinical means that countless hours, sets of eyes, thoughts, and improvements have contributed to a point where a treatment has been deemed enough to be tested with the most precious of life: children.

By writing this essay I am speaking on medical research and my experience with it. I am able to do so due to the fact that I have been lucky enough to come in contact with opportunities that cultivated my interest in medicine and research. Not all students have opportunities to get involved in research or participate in science related extracurriculars. In realization of this fact, I decided to host science seminars at a local after school program benefiting students from under-resourced communities. All researchers were once children. At some point in time something – a person, opportunity, experience– inspired them to pursue research.

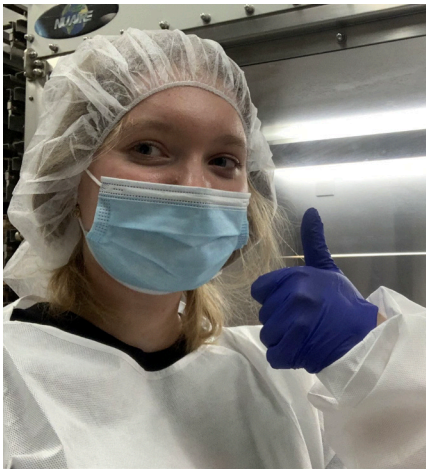
Who knows if any of my seminars' participants will become researchers…. Just like who knows what would have happened if I had not said hello to my fellow horseback rider….

Ella

Chicago, IL

Science seminar - strawberry DNA extraction lab - at a local non-for-profit organization benefiting underrepresented students.

April 2022



Assisting in pediatric cardiac research.

January 2022

SIMONE

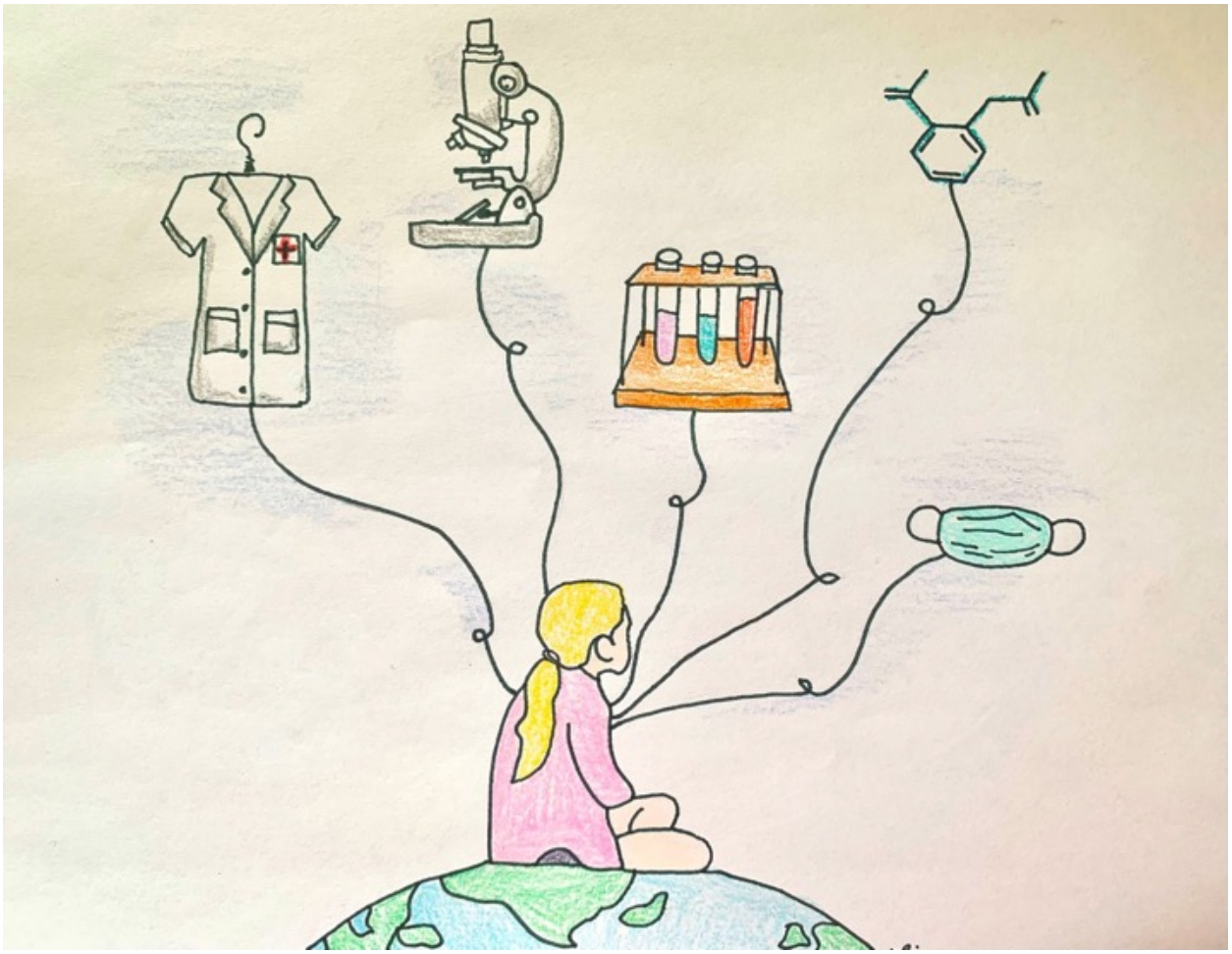
age 17

Simone, a highschooler, wanted to capture through her photography lens an important person at her local children's hospital. Christine Molina is a clinical research nurse at Ann & Robert H. Lurie Children's Hospital, and she ensures the safe administration of drugs that have not yet been approved by the FDA. In addition, she collects some baseline data for the drug's performance as she monitors patent health whilst they are on the drug. She plays a vital role in seeing any side effects that may have not been seen yet from the drug. Her training that prepared her specifically for the role of clinical research nurse, mainly stemmed from her working in the ICU, taking care of patients. This experience led her to realize the impact she wanted to make in patients' hopes for new treatments, as she was on the other side of the drug creation process, after they had been approved. A challenge she faces is when she finds that a drug she was helping test doesn't perform as originally hoped. However, she also says that with this challenge, she still experiences hope since she knows that this allows drug developers to explore other options and redistribute materials and resources to different venues.

OLIVIA

age 18

Olivia is a student studying Biology and Public Health. As a young patient and an advocate, Olivia knows that all facets of science, medicine, research, innovation and technology must be patient-centered. Without understanding patients' needs, nothing will work.



KALEE

age 17

Kalee titled her piece, "Bridge Over Troubled Water" as it represents her own perspective of living with diagnosed conditions and pursuing treatment through the use of clinical research trials. Kalee shares in her own words:

"This is what I think research and medical trials do, they build a bridge between doctors and parents/families/ kids to help with the scary stuff and help make kids healthier and better. It is the connection that brings us together."

MEREKI (ED) & VALERIA

ages 22 & 17

Mereki and Valeria's song illustrates the decision to join a clinical trial, and the emotions you may feel deciding to take this path. Mereki and Valeria share in their own words:

"At first you may be afraid or angry BECAUSE you will ask yourself many questions, but then you will grow strong, love and be loved. You just think that if it goes well, this drug will help many others like you. Don't be afraid or ashamed of your illness, it's what makes you special. Never lose hope!!"

SONG