The 411 on Research Participation

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Overview

- Research staff introductions
- Research coordinator (RC) responsibilities
- Determining patient eligibility
- Why research participation is important
- Research participant responsibilities
- Why people participate
- General study visit information
- More information

**Please note: For specific research questions, please visit our research table or call 650.736.0388**
Research Staff Introductions

Research Coordinators

Zoë Davies, NP, CCRC  
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Jacquelyn Zirbes, NP, CCRC  
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Colleen Dunn, RRT, CCRC  
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Cassie Everson, RRT, CCRC  
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Research Staff Introductions

Angie Leung
Regulatory Affairs Coordinator

Cathy Hernandez
Database Specialist

Alex Yacob, BS
Research Assistant
Research Coordinator Responsibilities

- Administrative tasks
- Subject-oriented tasks
- Safe
- Informed
Determining Patient Eligibility

- Inclusion/Exclusion criteria
- CFF database query
- Review medical history
- Clinical team involvement
- Contact patient
- Accept vs decline participation
Why Research Participation is Important

- New treatments
- Better quality of life
- Better understanding of CF
Research Participant Responsibilities

- Compliant
- Follow “rules”
- Close contact with medical team and research coordinators

I ❤️ Being Compliant

KEEP CALM & FOLLOW THE RULES
Why People Participate

- Altruistic
- Access to medications (it’s still research)
- Build relationships with RCs

Having the opportunity to participate in research studies has been such a blessing. Throughout my seventeen years of life, I’ve been in many studies. Whether it’s just filling out a quick survey, giving blood work or a sputum culture, or having to do months of testing out a new medicine, whenever I am asked to be in a study, my answer is always yes. The only way new drugs can get FDA approved and get out onto the market is for it to go through the clinical trials process. Clinical trials can’t happen and new medicines that can potentially improve the health of cystic fibrosis patients can’t be made available without "people participation". That’s why I say yes to every study I am eligible and asked to be a part of.

Living with a life threatening disease is hard work. I can go from 100% lung function one week to 80% the next. I am compliant with my daily treatments but that doesn't guarantee that a new bacteria won't enter my lungs. When I'm asked to test out a new drug, I feel like a kid on Christmas. Even though I don't know if I am getting placebo or the real deal, it's still just as exciting knowing that I could be receiving a medicine that could possibly change my life. If given the opportunity to change someone's life forever, wouldn't you do it? Participating in research studies is the best decision I have ever made and I hope that maybe just one person will read this and change their mind about being a part of changing and improving lives.
General Study Visit Information

- Compensation
  - Time
  - Gas or Travel Reimbursement (some sponsors provide)
  - Meals/Lodging Reimbursement

- Study Locations
  - CTRU: 800 Welch Road
  - Pediatric Clinic Research Room: 770 Welch Road, Suite 380

- Free Parking
- Same Team
Thank You!

We couldn’t do this without YOU!
Questions/Comments