

## SESSION RESOURCES: ENGAGING THE PUBLIC IN RESEARCH

This compilation of resources includes materials and websites that you can use to help educate your constituents about the research process and specific clinical studies.

### PARTICIPATING IN RESEARCH

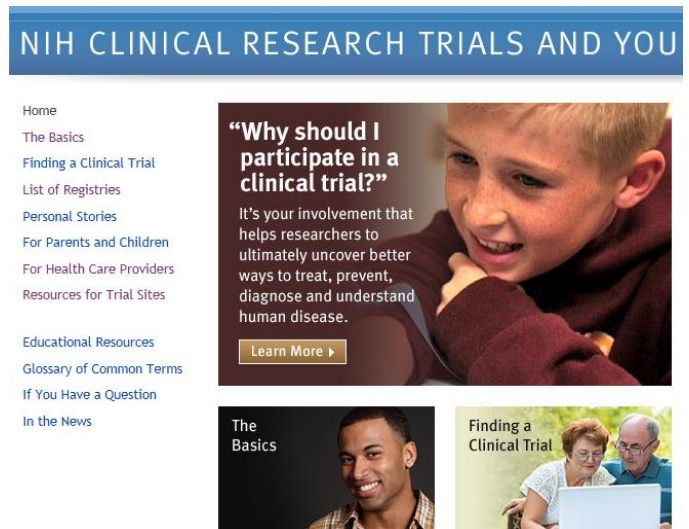
These resources provide background information about the research process and participating in clinical trials.

#### NIH Clinical Research Trials and You

<http://www.nih.gov/health/clinicaltrials/>

This National Institutes of Health (NIH) website provides a number of resources including:

- frequently asked questions about clinical research studies;
- videos of research volunteers and researchers telling their personal stories; and
- promotional materials to raise public awareness of clinical research, including posters and presentation slides.



#### Understanding Clinical Trials

<http://clinicaltrials.gov/ct2/info/understand>

This page of the ClinicalTrials.gov website provides frequently asked questions about participating in clinical trials, including what to consider before participating.

#### Clinical Trials

<http://www.nlm.nih.gov/medlineplus/clinicaltrials.html>

This MedlinePlus webpage provides links to a range of web resources, fact sheets, and tutorials about understanding clinical trials.

#### Be a Partner in Clinical Research: Help Others, Help Yourself

<http://newsinhealth.nih.gov/issue/mar2015/Feature1>

This *NIH News in Health* article describes how an individual's participation in research may help improve medical care.

#### Video: From Clinical Trials to Classroom Commitment, NIMH Expertise Benefits Students

<http://www.nimh.nih.gov/news/media/2012/from-clinical-trials-to-classroom-commitment-nimh-expertise-benefits-students.shtml>

In this NIMH video, a parent describes her son's experience participating in an NIMH clinical trial in Bethesda, MD.

## Providing Your Tissue for Research: What You Need To Know

<http://www.cancer.gov/publications/patient-education/providing-tissue>

This NIH booklet is for people who are thinking about donating their tissue to medical research. This booklet explains: what tissue is and why it is important for medical research; how tissue is collected and used; how privacy is protected; and the risks involved in donating tissue.

## PARTICIPATING IN RESEARCH: RESOURCES FOR SPECIFIC POPULATIONS

### Research for Women in Clinical Trials

<http://www.fda.gov/ForConsumers/ByAudience/ForWomen/ucm118508.htm>

This factsheet from the Food and Drug Administration, available in English and Spanish, describes what a clinical trial is and why it is important for women to participate in research.

### Building Trust Between Minorities and Researchers

<http://www.buildingtrustumd.org/>

This NIH-funded online educational program provides culturally tailored information for minority communities on how to become an informed decision-maker for participation in research, including clinical trials. The program also includes a curriculum for researchers and research staff to strengthen their capacity to effectively recruit and retain minority participants in research.

### Participating in Clinical Trials

<http://nihseniorhealth.gov/participatinginclinicaltrials/aboutclinicaltrials/01.htm>

The NIH Senior Health website offers background information about participating in clinical trials in an easy to read, plain language format for older adults.

### Children and Clinical Trials

<http://www.nhlbi.nih.gov/childrenandclinicalstudies/index.php>

This NIH website offers parents and healthcare providers an insider's guide to children's medical research. The website combines information about how clinical studies in youth are conducted with a video of children, parents, and healthcare providers discussing the rewards and challenges of participating in research.

The screenshot displays the 'Children AND CLINICAL STUDIES' website. At the top, there is a search bar labeled 'Search for Clinical Trials' and social media links for Contact, Connect, Share, and Español. The main content area features a video player with a play button overlay. The video shows three children (two boys and one girl) standing together. Below the video player, there is a caption: 'A documentary video for parents about enrolling their child in a clinical study.' and links for 'Show Video Transcript' and 'Download Video Options'. On the left side, there is a navigation menu with links: Home, Why It's Important, Participant Considerations, Getting Started, Once in a Study, Resources, and About this Site. On the right side, there are two text boxes with quotes from Dr. Renee Jenkins and Dr. Gall Pearson, and a yellow 'Explore' button with a magnifying glass icon and the text 'The Kids Files'.

## LOCATING TRIALS

Use these resources to search for NIMH- and NIH-funded trials.

### NIMH Clinical Trials—Participants

<http://www.nimh.nih.gov/trials/index.shtml>

NIMH supports research studies on mental health and mental disorders. Find specific studies being conducted across the U.S. that are currently recruiting participants by various disorders and conditions.

### ClinicalTrials.gov

ClinicalTrials.gov provides regularly updated information about Federally- and privately-supported clinical research for a wide range of diseases and conditions. ClinicalTrials.gov provides information about a trial's purpose, who may participate, locations, and phone numbers.

### Clinical Trials In Your State

[http://www.clinicaltrials.gov/ct2/results/map/click?term=Behaviors+and+Mental+Disorders\[CONDITION-BROWSE-BRANCH\]&recr=Open&fund=01&map.x=163&map.y=177](http://www.clinicaltrials.gov/ct2/results/map/click?term=Behaviors+and+Mental+Disorders[CONDITION-BROWSE-BRANCH]&recr=Open&fund=01&map.x=163&map.y=177)

Find current Federally-funded clinical trials in the area of behavioral health listed by state that are, or soon will be, recruiting. You can search for trials by clicking on your state in the map, or by scrolling down to your state for additional information.



## FINDING RESEARCH PROJECTS AND GRANTEES

Use these resources to identify NIH-funded grantees and projects.

### NIH RePORTER

<http://projectreporter.nih.gov/reporter.cfm>

RePORTER is a searchable database of Federally-funded biomedical research projects conducted at universities, hospitals, and other research institutions. Users can use RePORTER to search for scientific concepts, emerging trends and techniques, and to identify specific projects and/or investigators. Users can search for grants by state, Institute funded, keyword search, along with many other criteria.

Use RePORTER to identify projects for possible collaboration, or grantees that may be able to present about research studies at meetings and other events. The My RePORTER features allow users to save search results and criteria for future use, and create alerts when new projects are funded.

### NIH Research Portfolio Online Reporting Tool (RePORT)

<http://report.nih.gov/>

This NIH website offers quick access to reports, data, and analysis of NIH research and development activities. Simply browse or use one of the site's several search tools to access standard reports and data.

## NIH Clinical and Translational Science Awards

<http://www.ncats.nih.gov/cts>

The Clinical and Translational Science Awards (CTSA) program aims to strengthen and support the entire spectrum of translational research from scientific discovery to improved patient care. The more than 60 medical research institutions collaborate with community organizations throughout the research process to ensure that broad and unique community health needs are addressed.

## NIMH INTRAMURAL RESEARCH STUDIES

The NIMH Division of Intramural Research Programs (DIRP) conducts a large number of research studies with patients who have mental health disorders. The studies are performed at the NIH Clinical Center on the NIH campus in Bethesda, Maryland, and some of these studies recruit nationally for participants:

<http://www.nimh.nih.gov/labs-at-nimh/join-a-study/index.shtml>

**NIH Severe Mood Dysregulation Research Studies Enrolling Nationwide**

**Does Your Child Have Bipolar Disorder, Severe Irritability or ADHD symptoms?**

How do symptoms of severe mood dysregulation change as children grow up?  
What are the brain changes associated with severe mood dysregulation?

At the NIH Clinical Center in Bethesda, Maryland, several research studies are being conducted into the causes of bipolar disorder and severe mood dysregulation (SMD).

These studies use specialized testing and brain imaging to describe, over time, the moods and behavior of children with SMD and the brain changes associated with it.

All clinical evaluations, research procedures and visits are free of cost. Both parent and child must agree to the child's participation. Children and parents are compensated for participation. Travel and lodging expenses are paid by NIMH. Participants from across the country may be eligible to participate.

Those eligible to participate must be:

- Ages 7 - 17.
- Have chronic anger, sadness, or irritability, along with hyperarousal (such as insomnia, distractibility, hypersensitivity) and extreme responses to frustration (such as frequent, severe temper tantrums).
- Able to perform research & computer tasks and neuropsychological testing.
- In treatment with a physician, medically healthy, and not currently hospitalized, psychotic or suicidal.

**NON-TREATMENT RESEARCH STUDY**

Study participation begins with an initial outpatient evaluation that lasts one day. Subsequently, testing and brain imaging occur at visits which last two-three days, occur every two years, and continue until age 25.

**TREATMENT RESEARCH STUDY**

If unstable on current medications:

Your child may be eligible for a study testing the efficacy of different treatments for decreasing irritability in children with severe mood and behavioral problems.

Participant receives day or full hospitalization to discontinue medication, followed by either methylphenidate plus citalopram, or methylphenidate plus placebo.

- This study lasts 12- to 15-weeks.
- If clinically appropriate, participants who receive methylphenidate plus placebo will be offered the opportunity to receive methylphenidate plus citalopram at the end of the study.

**BiPOLARKids**  
Intramural Research Studies at NIMH  
FOR FURTHER INFORMATION,  
CALL: 301-496-8381

Ellen Leibenluft, M.D. or Kenneth Towbin, M.D.  
Email: [inlabkids@mail.nih.gov](mailto:inlabkids@mail.nih.gov)  
TTY: 1-866-411-1010  
<http://patientinfo.nimh.nih.gov>

NIH National Institutes of Health  
Department of Health & Human Services, National Institutes of Health, National Institute of Mental Health  
Protocol No. 12-00-0021 & 10-01-0024

The DIRP Marketing and Community Relations Unit is a resource for Partners to learn more about what studies are being conducted at the NIH campus and to obtain marketing materials to promote studies to your communities. For more information about DIRP studies:

- An announcement about a DIRP study recruiting participants nationally is included in the Update distributed on the first of each month.
- Study information is tweeted on the NIMH Twitter feed: <https://twitter.com/NIMHgov>.
- Sign up for email updates from DIRP Marketing and Community Relations Unit via NIMH GovDelivery announcements. To subscribe:
  - Select "Get Email Updates" from NIMH home page and enter email address.
  - Select "Intramural Updates" from the Subscription Topics.
- For Frequently Asked Questions about DIRP research: <http://www.nimh.nih.gov/labs-at-nimh/join-a-study/frequently-asked-questions.shtml>
- Contact Kalene DeHaut, MSW, Recruitment & Community Relations Specialist, 301-594-3188, [kalene.dehaut@nih.gov](mailto:kalene.dehaut@nih.gov).