

Join FRAXA

as we unite the global Fragile X community, raise awareness, and accelerate progress toward effective treatments and ultimately a cure for those living with Fragile X.





Global Initiative of FRAXA Research Foundation

July 22, 2024

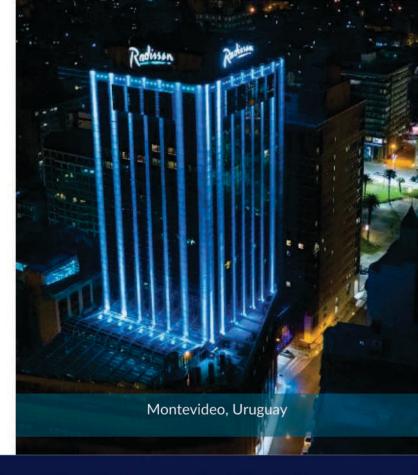
World Fragile X Day

World Fragile X Day celebrates families impacted by Fragile X syndrome. On July 22 we shine a light on this disorder by illuminating landmarks around the world and launching regional community events and media coverage.

World Fragile X Day began with FRAXA Research Foundation's vision of collaborating with experts and communities worldwide to galvanize biomedical research to change the lives of families everywhere.

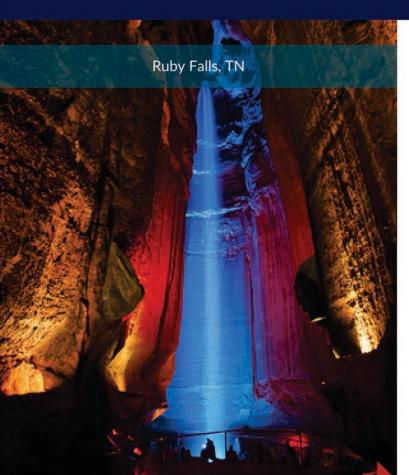
On July 22, 2021, World Fragile X Day exploded on the scene with 300 landmarks in 13 countries on 6 continents lit up for Fragile X. On that day, 5000 people also participated in the global webinar, "Fragile X Syndrome: In Pursuit of a Cure."

World Fragile X Day 2024 will reach millions of families, researchers, clinicians, and pharma/biotech professionals globally.



"As a family, we enjoy traveling throughout the city to see all of the bridges and buildings lit up in teal. It reminds us that Fragile X is bigger than our family and across the world, other families are feeling the same excitement as we are."

Jessica D., Florida



Fragile X Syndrome

Fragile X syndrome (FXS) is the most common inherited cause of autism and intellectual disabilities worldwide. Fragile X occurs when a single gene shuts down - a gene vital to normal brain function. There is no specific treatment or cure.

In 1994, three parents founded FRAXA Research Foundation when their firstborn sons were diagnosed with Fragile X. Since then FRAXA has become the global leader in accelerating research.

FRAXA Research Foundation is working to find effective treatments and ultimately a cure for Fragile X syndrome. Many of the worlds top neuroscientists agree that Fragile X research is key to solving the mystery of autism and other brain disorders.

Closing in on a Cure for Fragile X

We are seeing groundbreaking advances in Fragile X research. Here are some of the most exciting developments.



A Fragile X Clinical Trial Showed Intelligence Can Improve!

Two years ago a small trial of zatolmilast, funded by FRAXA Research Foundation and Tetra Therapeutics, showed significant functional improvements in adults. These improvements, achieved in just 3 months without undesirable side effects, are believed to be equivalent to a significant elevation in IQ. This is truly remarkable! The prospect of enhancing intelligence within a few months, with a conventional drug taken twice a day, seems almost like science fiction.

Large multi-center trials are underway. Could this new medicine also help people with other intellectual disabilities? We don't know yet, but FRAXA is now advising numerous pharmaceutical and biotechnology companies which are developing an array of drugs designed to enhance cognition.



Clinical Trials are Evolving and Expanding

Significant refinements have been made in clinical trial design to optimize and streamline the process. One example is at-home clinical trials, pioneered by Zynerba Pharmaceuticals and Harmony Biosciences. This changes the landscape: households who previously lacked access can now participate in Fragile X trials.



Definitive Therapies for Fragile X are Emerging

We are seeing incredible progress with treatment approaches that tackle the root cause of Fragile X syndrome: the lack of an essential protein normally produced by a single gene. These FRAXA-funded teams reported breakthroughs in the past year:

- Dr. Jeannie Lee at Harvard Medical School published two distinct methods to reactivate the Fragile X gene, one using CRISPR and the other using a drug combination.
- Dr. Joel Richter at the University of Massachusetts published a revolutionary new strategy that uses antisense oligonucleotides (ASOs) to indirectly reactivate the Fragile X gene by targeting the gene's messenger RNA.
- Dr. Kathryn Whitehead at Carnegie Mellon University adapted mRNA vaccine technology to spur brain cells to produce the Fragile X protein.
- Dr. Ray Turner at the University of Calgary has made substantial progress in optimizing protein replacement therapy for Fragile X syndrome.

FRAXA is now collaborating with large and small pharma companies on definitive treatments for Fragile X.



Community is a Powerful Force!

Community funding is the force behind the progress in Fragile X research. Other rare disease communities are now collaborating with each other and with pharmaceutical companies in unprecedented ways, following the FRAXA model. Rare diseases are gaining recognition because together they affect up to 30% of the world's population. Patient organizations like FRAXA are helping to developing new treatments with broad applicability.

All these exciting strides complement each other, collectively propelling Fragile X research forward to benefit everyone. Through collaborative efforts, supported by your generous contributions, together we will succeed!

FRAXA's Impact To Date



\$35 million





Pharmaceutical and biomedical partners



Teams Actively Researching

Research grants awarded

Direct Investment in Fragile X Research Fragile X Syndrome

Support World Fragile X Day on July 22, 2024

World Fragile X Day is a premier awareness event with exposure to millions of people around the world. Sponsors have unique opportunities to fund Fragile X research and increase their visibility among Fragile X families, researchers, clinicians, and pharma/biotech professionals.

We are eager to discuss your ideas. Please let us know how we can partner on this one-of-a-kind event. Contact Holly Roos, Community Services Director, at hroos@fraxa.org or Katie Clapp, President, at kclapp@fraxa.org.

Sponsorship Benefits	\$50,000	\$10,000	\$5000	\$2500
Custom opportunities! Talk to us!				
Featured in FRAXA seminars with direct exposure to the community				
Individualized consulting with experts in the Fragile X field				
Name and logo included on email blasts throughout WFXD campaign				
Social media spotlight				
Recognition on event t-shirt*				
Name and/or logo included in post-event recap on social movebsite, and email blast	edia,			
Name and/or logo included in pre-event social media camp	aign 🛑			•
Name and/or logo included on World Fragile X Day website				
*To guarantee recognition on the World Fragile X Day 2024 t-shirt, sponsorship must be received by May 30, 2024.				

"World Fragile X Day sees landmarks across our country join an international celebration."

Wendy Bruce, Fragile X Association of Australia



585 landmarks spanning 18 countries on 5 continents illuminated on July 22, 2023



Previous World Fragile X Day Sponsors





























Fragile X organizations around the world joined together as World Fragile X Day partners





































2023 Participating Landmarks

UNITED STATES

ALABAMA RSA Battle House Tower, Van Antwerp Building, Tuscaloosa City Hall & 6 more

ALASKA Lund House

ARIZONA Gilbert Water tower, Tucson Historic 4th Avenue Underpass, Eloy Water tower

ARKANSAS Union Plaza

CALIFORNIA

M on Box Springs Mountain,
San Jose Civic Center, UC Davis
MIND Inst & 2 more

COLORADO
Developmental FX, McNichols
Civic Ctr, City
and County of Denver Building

CONNECTICUT Lounsbury House

DELAWARE
Delaware State Capitol Building

FLORIDA Sunshine Skyway Bridge, Miami Tower, Curtis Hixon Park & 16 more

GEORGIA King and Queen Towers

HAWAII IBM Building

IDAHO
Zions Bank & JUMP Boise

ILLINOIS 875 North Michigan Ave, Wrigley Building, BCBS Building & 8 more

INDIANA
Martin Luther King, Jr.
Memorial Bridge & Unfinished
Block P Statue at Purdue

IOWA High Trestle Trail Bridge, Davenport Skybridge, Alliant Energy Tower & 5 more KANSAS Lied Center, South Kansas Ave arches

KENTUCKY Broadway Pedway, Helix Garage, Victorian Square Garage

LOUISIANA Caesars Superdome

MAINE Memorial Bridge

MARYLAND Baltimore Center Stage

MASSACHUSETTS
Zakim Bridge, Burns Memorial
Bridge, Longfellow Bridge & 3
more

MICHIGAN
Gross Pointe Shores City Hall,
Z-Deck, 321 Lafayette & 5 more

MINNESOTA I-35W Saint Anthony Falls Bridge, Sperry Tower, France Ave & 2 more

MISSISSIPPI
Gulf Coast Community College
STEM Building, The District at
Eastover

MISSOURI
James S. McDonnell Planetarium

NEBRASKA Bob Kerrey Pedestrian Bridge, Bridges Trust, Veridian Credit Union & 14 more

NEVADA Las Vegas City Hall, Keep Memory Alive Event Center

NEW HAMPSHIRE Hotel Concord, Memorial Bridge

NEW JERSEY
Ben Franklin Bridge, TRIAD1828
Centre, Union County Admin Bld
& 2 more

NEW MEXICO DoubleTree Hotel Albuquerque

NEW YORK Niagara Falls, Helmsley Building, The Metropolitan & 5 more

NORTH CAROLINA 550 S. Tryon, NASCAR Hall of Fame, Duke University Hospital & 3 more NORTH DAKOTA
Alerus Center

OHIO Rock & Roll Hall of Fame, Terminal Tower

OKLAHOMA
Tulsa Performing Arts Centre

OREGON Union Street Railroad Bridge, Oaks Park Adrenaline Peak rollercoaster

PENNSYLVANIA Ben Franklin Bridge, Philadelphia FMC Tower, Gulf Tower & 5 more

RHODE ISLAND Sakonnet River Bridge, Pawtucket River Bridge

SOUTH CAROLINA SkyWheel at Myrtle Beach, Rock Hill Water Tower

SOUTH DAKOTA World's Only Corn Palace, Vance Thompson Vision Halo

TENNESSEE Davidson County Courthouse, Ruby Falls, Gatlinburg Skylift Park

TEXAS Alamo Quarry Smokestacks, I-35 Bridge

UTAH Salt Lake City Hall Clock Tower

VIRGINIA
Virginia Aquarium & Marine
Science Center, Silverline
Center

WASHINGTON Two Union Square, Seattle Great Wheel

WASHINGTON 1625 Eye Street Building

WISCONSIN Lakefront Brewery, Bart Starr Memorial Bridge

WYOMING Marian H. Rochelle Gateway Center **GLOBAL ILLUMINATIONS**

AUSTRALIA Elizabeth Quay Bridge, Melbourne Star, Optus Stadium & 85 more

AUSTRIA
Danube Tower, Vienna Giant
Ferris Wheel

BRAZIL Itaipu Binacional, Cristo Redentor, Oscar Niemeyer Museum & 8 more

BRITISH ISLE
Douglas Promenade, Ramsey
Swing Bridge, Pulrose Power
Station & 2 more

CANADA
Niagara Falls, CN Tower, High
Level Bridge
RBC Convention Centre & 36
more

CHILE IEB, Tierra del Fuego

GEORGIA Tbilisi TV Tower

Venetian Loggia Building, Sitia

DENMARK Industriens Hus

Taj Mahal Tower, MLR
Convention Centre, Daiwik Hotel
Rameswaram & 36 more

IRELAND
Mansion House, Carmichael
Centre, Rock of Cashel & 1 more

ITALY / /

Porta del comune di anguillara

NEW ZEALAND

Michael Fowler Centre

Cascais City Hall

SOUTH AFRICA Fraser House, Shark Rock Pier, Hedges Home

UNITED KINGDOM
Ness Bridge, Titanic Museum
House, Mackay's Hotel & 9 more

<u>URUGUAY</u> Radisson Montevideo Victoria Plaza Hotel









