



PRISMS Clinic
and Research
Consortium

Smith-Magenis Syndrome Consortium Clinics



prisms

PARENTS AND RESEACHERS INTERESTED IN SMITH-MAGENIS SYNDROME

What You Should Know

Smith-Magenis Syndrome Consortium Clinics

What is the PRISMS Clinic and Research Consortium (PCRC)?

Clinics within the PCRC provide multi-specialty, comprehensive and compassionate care

for patients with SMS. The clinics provide families an opportunity to receive medical and clinical care and/or treatment recommendations that they can carry home to their local providers of care and that address the challenges and health concerns associated with Smith-Magenis Syndrome. The clinics' approach

to care includes consultation with other treatment specialists as needed while developing a plan of care for each patient that strives for health and well-being.

How many clinics are there?

There are currently eight clinic locations within the consortium.

They are located in California, Florida, Illinois, Massachusetts, Ohio, Pennsylvania, Texas, and Washington DC.

I don't see a clinic near me, will there be more clinics?

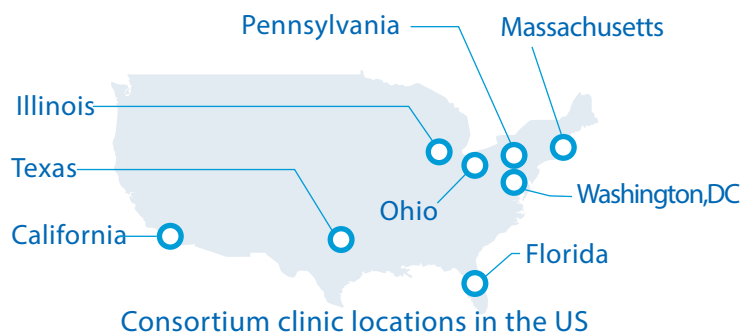
PRISMS is working to establish additional clinics throughout the U.S. Families can assist with this effort by informing PRISMS of any doctor, especially those affiliated with a hospital, who has demonstrated a consistent interest in SMS. PRISMS staff and advisors will then follow-up with the doctor to determine if they might be a good applicant to the PCRC.

How do I know which clinic I should go to?

Families should be aware that each clinic is unique and do not necessarily offer identical services. In most instances, families should plan to visit the nearest clinic. However, if you have questions about whether the clinic will be able to address your child's specific needs, we encourage you to reach out to the clinic using the contact information on the PRISMS website. Note that each clinic's medical and/or clinic director has a different background and, in most cases, you will find details about their training, experience



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and specialization on the hospital's website. Some clinics may provide telehealth visits, but specific rules and insurance restrictions may apply.

What does an SMS clinic visit include?

Each clinic will be different in how they structure a patient visit. All patients will be seen by a medical professional. Some clinics will arrange for any other needed specialists to be available on the day of the visit. Other clinics will provide a referral, or referrals, to other specialists and families will need to schedule follow-up appointments. Questions about what to expect during a clinic visit are best directed to the clinic coordinator in advance of the appointment.

Is there funding available for a clinic visit?

The PRISMS SMS Clinic Travel Fund Reimbursement Program supports families who need to travel to one of the clinics within the PCRC. This fund will help defray costs for travel, (airline or mileage support), lodging costs of other miscellaneous costs attributed to traveling to a clinic. This reimbursement is available to a family only one time. If you are planning a clinic visit and need financial assistance, please email info@prims.org for an application.

How much support does the reimbursement provide?

PRISMS will offer travel reimbursement up to \$300 if an application is approved. Approved funding will require receipts to be submitted and an expense form to be completed. A Proof of Clinic Attendance form must be signed by a clinic staff member and turned in with receipts to PRISMS. Please note that this funding does NOT cover the cost of the visit itself.

How do I make an appointment?

To make an appointment, simply call or email the clinic you wish to attend. All SMS clinic contact information is listed in this brochure and on our website. We encourage parents and other caretakers to clearly communicate their needs and expectations to clinic staff in advance of their initial appointment. You should be aware that some, if not all, clinics may offer a telemedicine option in lieu of in-person clinic visits. You may need to complete intake form, provide genetic testing and have access to prior medical records, labs and developmental testing, if available.

How long does it take to get an appointment with an SMS clinic?

Wait times vary from clinic to clinic, but, in some instances, families should be prepared to wait up to 6 months for a non-crisis appointment.

Clinic Contact Information

You can find an up-to-date listing of all of the consortium clinics and their contact information on our website at: <https://www.prisms.org/about-sms/living-with-sms/sms-clinics/>

SAN DIEGO, CA San Diego Pediatric Neurology/ Smith-Magenis Clinic Rady Children's Hospital

Address:
3030 Children's Way
San Diego, CA 92123
Ages seen: All
Clinic Director: Dr. Gail Reiner, DNP, FNP-C
Physician Consultant: Kristen Wigby, MD
Clinic Coordinator: Janice Balagtas
Email: gereiner@health.ucsd.edu
Phone: 858-966-5819
Web: <https://www.rchsd.org/>

CHICAGO, IL Smith-Magenis Clinic Rush University Medical Center

Address:
1725 W. Harrison Street, Suite 718
Chicago, IL 60612
Ages seen: Children and Adults
Medical Director: Elizabeth Berry-Kravis, MD, PhD
Clinic Coordinator: Angel Wang
Email: angel_wang@rush.edu
Phone: 312-942-4036
Web: <https://www.rush.edu/>

LEXINGTON, MA (Greater Boston) Lurie Center for Autism Massachusetts General Hospital MassGeneral Hospital for Children

Address:
1 Maguire Road
Lexington, MA 02421
Ages seen: All
Medical Director: Ann Neumeyer, MD
Email: LurieCenter@partners.org
Phone: 781-860-1730
Web: www.luriecenter.org

LEWISBURG, PA Geisinger SMS Clinic Geisinger Department of Developmental Medicine

Address:
120 Hamm Drive
Lewisburg, PA 17837
Ages seen: Children and Adults
Clinic Director: Barbara Haas-Givler, MEd, BCBA
Medical Director: Thomas Challman, MD
Clinic Coordinator: Megan Zieber, MS, MPH, LGC
Email: mzieber@geisinger.edu
Phone: 570-551-6968
Web: <https://www.geisingeradmi.org/>

HOUSTON, TX Smith-Magenis Syndrome Clinic Texas Children's Hospital

Address:
6701 Fannin Street, 16th Floor
Houston, TX 77030
Ages seen: All
Clinic Director: Rachel Franciskovich, MS, CGC
Medical Director: Lorraine Potocki, MD, FACMG
Clinic Coordinator: Rachel Franciskovich, MS, CGC
Email: smsclinic@texaschildrens.org
Phone: 832-822-2100
Web: <https://www.texaschildrens.org/>

WASHINGTON, DC Smith-Magenis Syndrome Multidisciplinary Clinic Children's National Hospital

Address:
Takoma Theater
6833 4th Street NW
Washington, DC 20012
Ages seen: 6 mos. to 65 yrs.

Medical Director (acting):
Sinan Omer Turnacioglu, MD
Temporary Clinic Coordinator:
Sinan Omer Turnacioglu, MD
Email: Sturnaci@childrensnational.org
Phone: 202-476-6249
Web: <https://childrensnational.org/departments/center-for-neuroscience-and-behavioral-medicine/programs-and-services/neurogenetics-program>

GAINSVILLE, FL UF Center for Autism and Neurodevelopment Smith-Magenis Syndrome Clinic

Address:
4197 NW 86th Terrace, 3rd Floor
Gainesville, FL 32606
Ages seen: Lifespan
Clinical Director: Kerri Peters, PhD, BCBA-D & Timothy Vollmer, PhD, BCBA-D
Medical Director: Takahiro Soda, MD, PhD, FAPA
Clinic Coordinator: Mary Kleckner, MSW
Email: UFCAN-referrals@shands.ufl.edu
Phone: 352-265-9177
Web: <https://ufhealth.org/locations/uf-health-center-for-autism-and-neurodevelopment#>

CINCINNATI, OH Cincinnati's Children's Hospital Neurobehavioral Psychiatry Clinic SMS

Address:
5642 Hamilton Avenue
Cincinnati, OH 45224
Ages seen: Children (0-17.5 years old)
Medical Director: Katie Harris, MD
Email: neurobehavioral.clinic@cchmc.org
Phone: 513-636-6553
Web: [Cincinnati Children's Hospital Medical Center](http://CincinnatiChildrensHospitalMedicalCenter)
www.cincinnatichildrens.org

