



Directory of Medical Resources for Diagnosis & Treatment of Catatonia in DS

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DATA

RESULTS

BACKGROUND

1. A lack of physicians willing to provide diagnostic evaluations and treatment for adolescents & young adults with DS who develop catatonia and other causes of regression poses a major health threat.
2. Adult psychiatrists shy away from treating individuals with neurodevelopmental disorders and feel ill-equipped to navigate regression's complex diagnostic paradigm.
3. Our "open access" articles describing Catatonia in DS prompted families to contact us for medical referrals.
4. Fortunately, recent literature iterates clear information on differential diagnosis, treatment options, clinical course & prognosis for catatonia in DS.
5. We networked with physicians across the country to locate physicians willing to manage these patients.
6. Most University Hospitals have resources to diagnose & treat patients, but lack coordination.

OBJECTIVES

1. Develop a Directory of Physicians and/or Medical institutions who will accept patients with DS and catatonia for diagnostic evaluations, treatment and ongoing follow-up.
2. Find a "home" for the Directory, so it can grow & serve more families.

METHODS

1. When we were contacted by families or physicians looking for DS catatonia care, we created a database of resources who agreed to accept each patient.
2. The database is separated into families and/or physicians requesting a referral.
3. We explored medical options in their area, often tracking 2nd and 3rd source referral options.
4. Phone calls let us determine their needs.

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Referral Options by State

State	Medical Institution	Clinic	Name	Specialty	email	Contact Person	Previous patients	Restrictions age, in state, etc
Missouri								
St Louis								
Columbia								
Kansas City								
California								
Irvine								
Los Angeles								
Oakland								
Sacramento								
Colorado								
Denver								
Georgia								
Atlanta								
Illinois								
Chicago								
Park Ridge								
Indiana								
Indianapolis								
Kansas								
Univ. Kansas								
Wichita								
Kentucky								
Lexington								
Maryland								
Baltimore								
Massachusetts								
Boston								
Worcester								
N. Carolina								
Ohio								
Toledo								
Michigan								
Ann Arbor								
Minnesota								
Eagle Lake								
Pennsylvania								

In the 1960s when Medical Genetics was young, the Am. Society of Human Genetics set up a website listing information for Genetics Clinics, which was updated annually. Run by a stellar Geneticist in Seattle, Bonnie Pagon, it changed the trajectory of Medical Genetics. In 2000, it was adopted by NIH & continues to connect families, physicians & geneticists with services.

Also, New York (NYC), Tennessee (Memphis)

1. 39 families seeking evaluation & treatment of their child with DS and Catatonia. All had read 2019 article: Catatonia in Down syndrome: systematic approach to dx, rx and outcome, Miles JH.
2. 21 families given local medical referrals.
3. 24 MDs & 4 NP/SLP agreed to take new patients.
4. Encouraged forming multidisciplinary teams within institutions &/or cities. (3 teams formed)
5. Telephone conversations covered wide range of questions, similar to new clinic visit. Families shared information re. resources in their city/area.
6. Families were sent packets describing diagnostic protocol, treatment strategies and references. Physicians were sent more in-depth information pertaining to recommended diagnostic considerations, data collection & treatment guidelines.

CONCLUSIONS

1. Parents may go years trying to determine what caused their child's regression.
2. Most young adults with DS are not linked with DS resources.
3. Physicians "tend" to disregard current studies and treat Catatonia as a symptom, rather than a syndrome, leading to risky polypharmacy.
4. DSMIG has the resources including the expertise, established website, medical professionals directory to make information available to both families.
5. Additional resources needed: A) Standardized Databases of families looking for medical providers & programs willing to provide care. B) Guidelines for diagnosis and care; C) referral mechanism, D) Persons willing to track down appropriate referrals. E) Linkage with all DS resources in US.
6. Partnership with DS resource groups &/or NIH would be ideal.