

# ANGELMAN CLINIC WITHOUT WALLS

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Rady Childrens Hospital, San Diego & UCSD

# Services:

## **Via Rady Childrens Hospital Clinics**

- Genetics – Lynne Bird
- Neurology/Epilepsy– Mark Nespeca
- Gastroenterology – Rebecca Cherry
- Nutrition/dietician (LGIT, Keto, Atkins) Vanessa Aldaz
- Orthopedics – Hank Chambers, Maya Pring
- Speech/communication therapy - C.Dabasinskas
- Behavioral Assessment and therapy (also see adults) – Ayala Ben-Tal; Abbey Hye

## **Via UCSD Clinics:**

Neurology/Epilepsy plus referral to other medical services if needed

# Process A:

Parent contacts administrative staff (Marlene) and defines

- a) Which provider(s) they wish to see during the visit
- b) Information re: insurance obtained from parent and authorization pursued
- c) When authorization finalized then dates offered (2<sup>nd</sup> and 4<sup>th</sup> weeks of the month)
- d) Appts booked
- e) For “new” adult patients, Neurologists at UCSD Drs.Kansal and Dr.David Lee will see patients wishing Neurology visits – if other adult medical specialties needed referral could be made to e.g. Ortho or GI

# Process B

- Preserved clinic slots for Mondays/Tuesdays
- Close in main campus sites: Neuro, Genetics, Ortho, GI, Nutrition
- 1 mile away - Behavioral Assessment/Therapy; Speech
- UCSD Clinics are 4.5 or 9 miles from RCHSD and 20-40 minute drive in daytime
- Each provider will provide After Visit Summary – in future Open Notes may become operational at RCHSD
- Families will be encouraged to sign up for MyChart EPIC access to view visit notes/recommendations
- Summary of all visits/recommendations will be composed and mailed to family and PCP

# Other aspects:

- Provide volunteered personal contact phone numbers of several San Diego families who care for Angels to those visiting and not connected with others
- Option to engage in Natural History Study Visit during visit to RCHSD
- **Goal:** To provide sustainable AS clinical consultative and direct care service beyond termination of seed grant from ASF
- **Future:** Med/Peds trained Neurodevelopmental Disabilities Specialist; Ped Physiatry; Ped Sleep Medicine

# Experience 1.5 years: San Diego AS Clinic Without Walls

- Many HMOs will not authorize visit
- Many such families opt for Natural History Visit and not seek consultation with other services
- Most > 50 miles distant – longest 1800 miles
- 14 authorized patients requested services:
  - Neurology: 14
  - Speech/Communication: 3
  - Behavior: 2 (insurance denied several)
  - Nutrition/Diet Therapy: 2
  - Orthopedics, GI - none