ANGELMAN CLINIC
WITHOUT WALLS

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\textsuperscript{nd} and 4\textsuperscript{th} 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