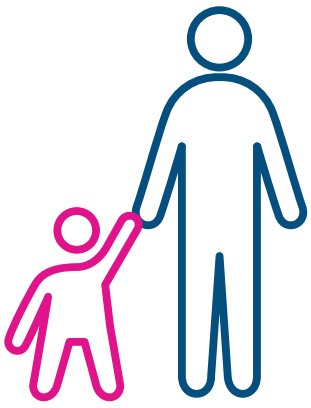
angelman SYNDROME FOUNDATION

The Comprehensive Care Binder

For _____



1

General Information

General Info

Name: _____

Address: _____

_____

Birthdate: _____ SSN: _____

Parent/Guardian #1: _____

Address: _____

_____

Email: _____ Phone: _____

Parent/Guardian #2: _____

Address: _____

_____

Email: _____ Phone: _____

Insurance Coverage

Does the individual with AS have any of the following:

- ☐ Private Insurance
- ☐ Medicaid
- ☐ Dental Insurance
- ☐ Vision Insurance

Include copies of all insurance cards with Member ID/Number, Group Number, Policy Holder and Policy Holder DOB

Additional Information

*Is Secondary Insurance provided by a Deeming Waiver? ☐YES or ☐NO

If YES, make sure to include renewal process and as much information as possible about this renewal process (attach separately).

Are there any regular meetings in regards to insurance and/or waivers? ☐YES or ☐NO

Name	Role *(parent/sibling/teacher/nurse/bus driver/respite)*	Phone	Email

Medical Information

Documents

- ☐ Copy of Birth Certificate
- ☐ Genetic Diagnosis Test Results
- ☐ Vaccine Record
- ☐ Past Medical History, including but not limited to seizure log, surgeries, hospitalizations, major illnesses, medications (past and present), previously prescribed meds that were ineffective, seizure protocol and seizure action plan.

General Doctors/Physicians/Specialists

Primary Physician: _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits/What Months: _____

Labs Ordered: _____

Medicine Prescribed (dosage/frequency): _____

Questions: _____

Accepts Insurance: _____

Other: _____

Dentist: _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits: _____

Sedation Needed: _____

Dental Insurance: _____

Questions: _____

Future Dental Procedures? _____

Other: _____

General Doctors/Physicians/Specialists

Neurologist: _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits/What Months: _____

Labs Ordered: _____

Medicine Prescribed (dosage/frequency): _____

Questions: _____

Accepts Insurance: _____

Other: _____

GI Doctor: _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits/What Months: _____

Labs Ordered: _____

Medicine Prescribed (dosage/frequency): _____

Questions: _____

Accepts Insurance: _____

Other: _____

Ophthalmologist : _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits: _____

Glasses Perscription? _____

Vision Insurance: _____

Questions: _____

Future Eye Exams/ Procedures? _____

Other: _____

General Doctors/Physicians/Specialists

Orthopedist : _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits: _____

Reason for Visits: _____

Questions: _____

Accepts Insurance: _____

Other: _____

Specialist: _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits/What Months: _____

Labs Ordered: _____

Medicine Prescribed (dosage/frequency): _____

Questions: _____

Accepts Insurance: _____

Other: _____

Specialist: _____

Address: _____

Phone: _____ Fax: _____

Frequency of Visits/What Months: _____

Labs Ordered: _____

Medicine Prescribed (dosage/frequency): _____

Questions: _____

Accepts Insurance: _____

Other: _____

Additional Info:

Therapies

Type of Therapy: _____ Name: _____

Address: _____

Phone: _____ Fax: _____

Schedule: _____

Payment (Insurance or SP): _____

Additional Information: _____

Type of Therapy: _____ Name: _____

Address: _____

Phone: _____ Fax: _____

Schedule: _____

Payment (Insurance or SP): _____

Additional Information: _____

Type of Therapy: _____ Name: _____

Address: _____

Phone: _____ Fax: _____

Schedule: _____

Payment (Insurance or SP): _____

Additional Information: _____

Type of Therapy: _____ Name: _____

Address: _____

Phone: _____ Fax: _____

Schedule: _____

Payment (Insurance or SP): _____

Additional Information: _____

Medications/Prescriptions

Name *(Generic or Brand)*	Dosage	Frequency	Quantity *(30/90/120 day supply)*	Cost	Pharmacy	Purpose	How is the medication taken?	Preparation Type: *(pill, capsule, liquid, chewable, sprinkle, etc)*	Comments/Notes: *(ex: does it need to be brand necessary)*

Seizure History Log

Date	Time	Length of Seizure	Medication Administered/Actions Taken	Notes and Important Information

3

Adaptive Equipment/DME (Durable Medical Equipment)

List any adaptive equipment, devices and durable medical equipment (i.e., walker, wheelchair, car seat/harness, C-Pap machine, orthotics, iPad, communication device, glasses, etc.)

Adaptive Equipment/ Device	Who Prescribes?	How is it funded?	Who is involved? *(ex: prescription from doctor or therapist?)*	Additional Information:

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Important Personal Care Information

Important Personal Care Information

Include information regarding your adult individual with AS personal care and hygiene.

Examples include but not limited to:

– Incontinence service for adult diapers and pads

- Name & contact info of company:
- How often do you need to order?

– Hair cuts

- Where does your individual with AS get his/her hair cut?
- Frequency?

– Nail Trim

- Who cuts individual's nails?
- How often?
- Tips:

– Information on shaving (male and female).

– Things to frequently check on (whether individual lives at home or in residential setting):

- Skin assessment: any irritated spots, or infected bumps?
- Frequency of bowel movements
- Changes in behavior
- Changes in appetite

Additional Information:

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Weekly Schedule

Saturday					
Friday					
Thursday					
Wednesday					
Tuesday					
Monday					
Sunday					

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IEP/ISFP

Include copies of current IEP

Information to list:

– When are annual meetings to review goals (month of the year)?

– Who is on the IEP/ISFP Team:

Additional information:

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Financial Information

Financial Information – Include any account that directly impacts the individual with AS

Bank/Savings Account: _____

Name(s) on Account: _____

Banking Institution: _____

Specific Location that you currently use: _____

Account Number: _____

Routing Number: _____

**or attach voided check*

Who Manages account? _____

What are asset limits to this account? _____

**Balance for Bank/Savings and SS/SSI needs to remain below a certain amount as not to disqualify him/her from any Waiver program and Medicaid.*

ABLE Account: For more information visit https://www.ssa.gov/ssi/spotlights/spot-able.html

Name/s on Account: _____

Banking Institution: _____

Account Number: _____

Routing Number: _____

Beneficiary: _____

**Include document about Rules of an ABLE account—especially maximum deposit limits AND what it can be used for. Varies by state.*

Special Needs Trust

Name/s on Trust: _____

EIN: _____

Rules Related to Trust: What can it be used for and tax information

_____

Accountant and/or Attorney Name and Contact Information

_____

Financial Information – Include any account that directly impacts the individual with AS

SS/SSI Account/Deposit: _____

Amount deposited each month: _____

Where is SS/SSI Deposited: _____

Rules for SS/SSI Direct Deposit: _____

Who is Representative Payee: _____

**Balance for Bank/Savings and SS/SSI needs to remain below a certain amount as not to disqualify him/her from any Waiver program and Medicaid. For more information visit https://www.ssa.gov/benefits/ssi/*

Other Insurance Policies:

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Legal Documents & Paperwork

Legal Documents and Paperwork

– Birth Certificate

– Passport

– Social Security Card

– Copies of updated Wills for Parents of Individual with AS

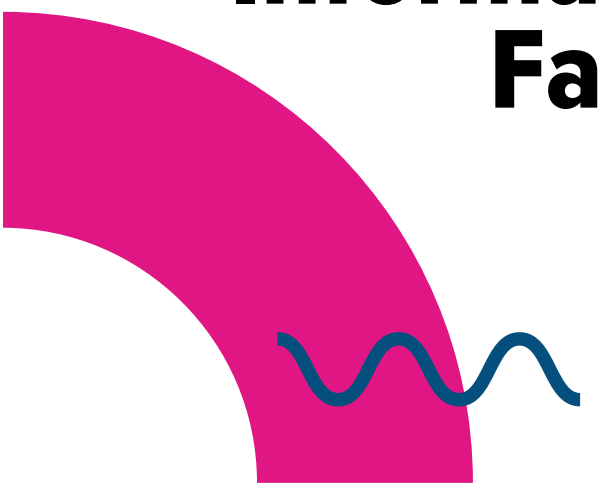
– Guardianship Paperwork

– Medical Power of Attorney for Parents

– Trust Documents and Information that Benefit Individual with AS

– Copies of Any Waiver Documents

List & Contact Information of Close Family/Friends



List and Contact Information of Close Family/Friends

Name: _____

Phone: _____

Email: _____

Name: _____

Phone: _____

Email: _____

Name: _____

Phone: _____

Email: _____

Name: _____

Phone: _____

Email: _____

Name: _____

Phone: _____

Email: _____