Rare Passport

See page 3 for **critical alerts** and **red flags**

Identity and contact

Personal Details

Full name

Nickname/preferred name

Date of birth [DD / MM / YYYY]

Sex (as recorded at birth)

Gender identity

Preferred pronouns

Patient Identifier(s)
(e.g. Medical Record number (MRN); Unit Record (UR) number)

Medicare number IRN

Expiry /

Address

Primary contact (call FIRST)

Full name

Relationship

Preferred language

Telephone Number

Email

Secondary contact

Full name

Relationship

Preferred language

Telephone Number

Email

Consent/decision-maker

Rare or undiagnosed condition

Name of condition

Additional diagnoses/co-occurring conditions

About the condition (general)

How it presents in this child/young person, and any family

Main therapeutic approach for this child/young person

Where to find more information

Critical alerts and red flags READ FIRST

Allergies and isolation status

Medication and anaesthesia alerts

Other relevant management plans that require review

Things that help care go well

Sensory and communication supports

Medical considerations

Awesomeness report

Inspired by Rachel Callander's Awesomeness Form (Super Power Baby Project), originally created as "Evie's Awesomeness" for her daughter Evie. The questions below are deliberately phrased so they can be answered **YES** — a reminder that this person is a child or young person, not a list of deficits.

Learn more or download the "How to make an Awesomeness Form" booklet at https://rachelcallander.com/

These questions and answers should be written with the child or young person, in their own words wherever possible, and their parent/support person if appropriate.

Question:

Answer:

Question:

Answer:

Question:

Answer:

Question:

Answer:

Care team

Name	Role or Specialty	Department or Organisation	How to contact	Passport shared
				◯
				◯
				◯
				◯
				◯
				◯
				◯
				◯
				◯
				◯
				◯
				◯
				◯

Current goals and priorities – what matters right now

Top three child/young person and family goals and priorities

1

2

3

School and national disability insurance scheme

Type of schooling/supports

National Disability Insurance Scheme plan

Diet and eating plans (only if clinically relevant)

Diet and eating plans

Clinical research (optional)

Research and registries

Support groups and trusted resources

Patient and family support

Sign-off and version control

Completed by

Date completed

Next review date

Signature/Stamp

To sign, select Fill & Sign → Add signature, then place your signature above.

This Rare Passport was co-designed with people living with rare conditions and their clinicians across Australia. It forms part of a Rare Condition Passport and Toolkit (available at rarediseasesnsw.au/), which also includes a de-identified template, guide to completion, and guidebooks for families living with a rare or undiagnosed condition.

It is intended to help support a family and their coordinating clinician share important information about a child or young person living with a rare condition.

Rare Diseases NSW

The latest clinical updates, medication and doses etc **MUST be checked** with the young person and their parent/primary caregiver and checked against the hospital, outpatient and/or primary care medical records and documentation.

Stay up to date with Rare Diseases NSW at rarediseasesnsw.au/connectwithus/

We'd love to hear any feedback about this passport from any patient, family or clinician. Scan the QR code to register your interest in helping to improve and evaluate the Passports.