

Summary of presentation for:

‘Rare Disease Workshop’

INTO THE UNKNOWN
Living with chILD – Our Journey with Sarah

Presented by the Walker Family

In the Beginning

- Birth and initial hospitalisation
- Finding a diagnosis
- Adjusting to life at home

Surviving the First Two Years

- Constant illness and hospital admissions
- Feeding issues
- PEG placement

The S-Team

- Who is part of Sarah’s care team

A Hospital Ward At Home

- Life with a chronically ill child

Full-Time Job

- So much to do, so little time

Strapped For Cash

Imagine

- Take a walk in our shoes

The Good, the Bad and the Even Badder

- Our thoughts on the health care system

Who Ya Gonna Call

- Handy contacts and information

Saving Our Sanity

- How we’ve changed as people and as a family

A New Day

- What does the future hold for Sarah

Questions and Photo Gallery