Welcome – and thank you!

Thank you for being part of the study and helping us to answer important questions about WHAT happens to children with uveitis, and WHY.

The information we are collecting will be used to help families affected by childhood uveitis so that we can improve outcomes.

On page 3 we report results from the first round of questions we asked families about how uveitis has impacted their life.

Have you returned your questionnaires?

We want to make sure we hear the voices of those affected by childhood uveitis.

Please don’t forget to return them – if you have lost them, email us (see contact details below) and we can send you new copies!

Study Update

<table>
<thead>
<tr>
<th>Hospital sites</th>
<th>Patients recruited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Target 41</td>
<td>Target 250</td>
</tr>
<tr>
<td>32</td>
<td>194</td>
</tr>
</tbody>
</table>

UNICORNS – C19

We aimed to describe the impact of the pandemic for families of children newly diagnosed with uveitis.

Our findings are on page 2, and our report should help plan future services for vulnerable patient groups during disruptive times.
Responses from 51 families:

61% expressed concern over the impact of the pandemic on their health, 31% expressed difficulties in accessing essential medication, and 61% found it harder to get basic food items.

Despite this, the majority expressed a positive experience with NHS services, with 74% being comfortable using their specialist hospital during the pandemic. **Key themes were:**

- **Safety procedures**
  - "We already there monthly. Everyone is taking the right precautions to make the appointments covid safe”

- **Adoption of digital health tools (across 1° to 4° care)**
  - "Very good solutions blending face to face appointments with virtual appointments. Diagnosis, treatment and care were not compromised”

- **Challenges co-ordinating care**
  - “They [local hospital] didn't have any knowledge about JIA or uveitis”
  - Need for tools to support delivery of co-ordinated care

- **Challenges in delivering telemedicine for rare disease**
  - “May have to see different staff to usual which often means to tell the whole story again!”
  - Need for tools to support non-specialists co-managing rare disease

- **Use of immunosuppression**
  - “With his immune system compromised due to the medication it [covid] is scary”
  - Need for improved dissemination of research findings amongst families
Patient Reported Outcome Measures

How is childhood uveitis affecting families around the time of diagnosis?

**STRENGTH & DIFFICULTIES QUESTIONNAIRE (SDQ)**

This measured how well families cope with their diagnosis – usually, we would expect 20% of families who answer this to express concerns

- 20% of parents with children aged 2-4 expressed concern around how well their children cope with things
- 44% of parents with children aged 4-11 expressed concern around how well their children cope with things
- 44% of children aged 11-17 expressed concern around how well they cope with things

**CHILD SLEEP HABIT QUESTIONNAIRE**

This measured behaviours linked with sleep difficulties.

A third (33%) of families reported sleep related problems

**CHILD HEALTH UTILITY**

This measured how children feel on an average day with the sum being on a scale of 0 (worst) to 1 (best)

Families reported that children on an average day feel good to great with numbers ranging from a minimum of 0.6 to maximum of 1

---

The average score at diagnosis was 89/100, however the range is wide. But children did report 5% higher in comparison to their parents
The CHOIR study is on its way! We plan on collecting samples from children who have inflammation in and around their eyes.

This is in order to help researchers look for signals from those tissues and see whether those signals tell them what causes disease, which treatments work best, and what happens to children with different types of disease.

These signals will be discovered by testing for different types of cells and proteins, and genetic testing. We will also look at stool (‘poo’) to see what kind of ‘friendly bacteria’ children have inside them.

Big, complex studies like this can take a few years to plan and to get the funding that’s needed. We will let you know when we are able to start it.

**STUDY DAY**

We recently held the Childhood Uveitis day for UNICORN families. Thank you to all the families who attended in person and online.

Here is a [link](#) to the videos from the day.

---

Find us on social media

If you would like to keep up to date on all our latest news, future events, research and findings, visit our website or follow us on social media

@UVEITISUNICORNS (for families)
@UVEITISUNICORN_YP (for young people)

On youtube search for ‘Childhood Uveitis’

---

Contact us for more info:

UNICORNs team
UCL Great Ormond Street
Institute of Child Health
30 Guildford Street
London WC1N 1EH

+44 20 3987 2163
unicorns@ucl.ac.uk
https://www.ucl.ac.uk/child-health/unicorns