



CITRIN FOUNDATION QUARTERLY NEWSLETTER

We hope you enjoy the Summer Edition of our patient newsletter where you will find updates on our patient initiatives and a summary of the resources we have rolled out in the last three months.

PATIENT LEAFLETS

Birthday food flyer

Building upon the launch of our recipe section at the beginning of this year, we wanted to create a resource to help parents with planning birthdays by developing recipes that balance citrin deficiency (CD) dietary requirements, flavour, and ease.

Workplace flyer

Workplaces have a duty to their employees' well-being, but sometimes it can be difficult to understand the needs of employees, especially those with rare diseases. As a contribution to helping to make workplaces more inclusive spaces for people living with citrin deficiency, we created this resource for our members to share with their employers if they wish.

All leaflets are available to download from our patient website.



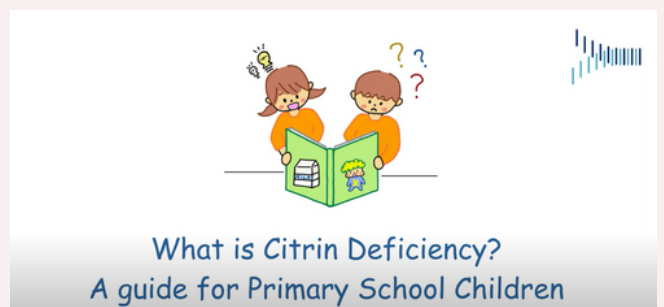
YOUTUBE CHANNEL LAUNCH

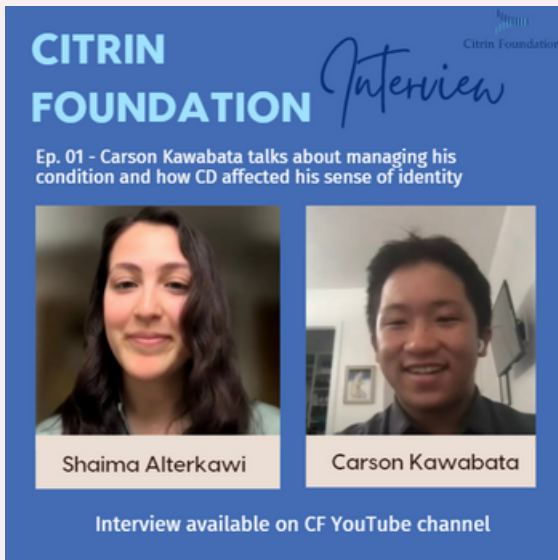
In April, The Foundation launched a YouTube channel to share resources in a visually engaging and easily digestible format which we believe will be valuable to our members as well as professionals or members of the general public who would like to learn more about CD.



GUIDE FOR PRIMARY SCHOOL CHILDREN

As part of our drive towards building more age-specific resources, we created a short video guide aimed at primary school children to help explain citrin deficiency. We partnered with one of our Japanese members, Himene Asatsuma to illustrate this resource and have received incredibly positive feedback from our membership.





We also launched our interview series. In the first episode, our Patient Engagement Manager speaks to Carson Kawabata, an inspirational citrin deficiency patient and very active member of our community. Carson talks about managing his condition and how CD has affected his sense of identity and his relationships with others. An article version of the interview will soon be made available in Japanese.

For our second episode, we welcomed Himene Asatsuma, a citrin deficiency patient living in Tokyo, Japan who illustrated the above-mentioned resource. Himene talks about how she gained understanding from her peers in her own way and her thoughts on living with citrin deficiency. The episode ends with a powerful message from Himene to children with CD. An article version of the interview will soon be made available in English.

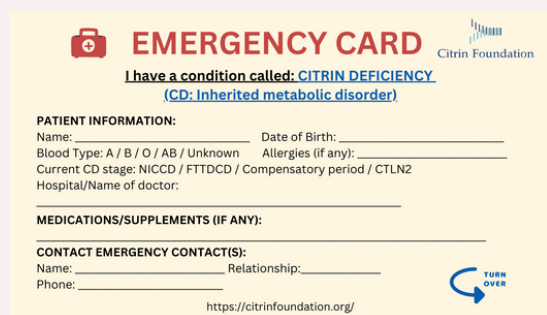
MULTI-LANGUAGE RESOURCES

As we continue to work towards our mission of finding a cure, it has become increasingly apparent that one of the next big steps in achieving this goal is to offer our resources in different languages to ensure that we reach patients who may not speak English or Japanese. We are delighted to announce the launch of our Multi-Language Resource Hub on our website, now offering our citrin deficiency patient flyer in German and Korean. We have plans to expand this initiative to include the following languages: Arabic, Vietnamese, Thai and Chinese. If you would like to volunteer as a proof-reader/translator, please get in touch at patients@citrinfoundation.org.



EMERGENCY CARD

The patient engagement team has designed a wallet-sized patient emergency card. This card provides crucial information about the patient and their condition to ensure rapid and accurate medical attention during emergencies.



EMERGENCY CARD Citrin Foundation

I have a condition called: **CITRIN DEFICIENCY**
(CD: Inherited metabolic disorder)

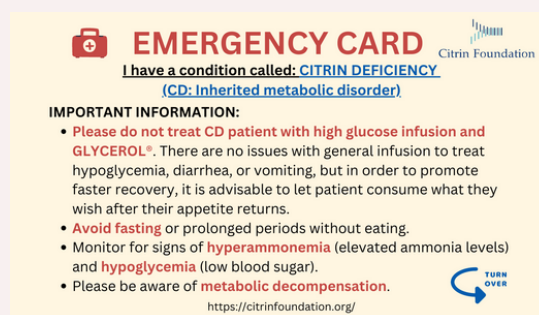
PATIENT INFORMATION:
Name: _____ Date of Birth: _____
Blood Type: A / B / O / AB / Unknown Allergies (if any): _____
Current CD stage: NICCD / FTTDCD / Compensatory period / CTLN2
Hospital/Name of doctor: _____

MEDICATIONS/SUPPLEMENTS (IF ANY):

CONTACT EMERGENCY CONTACT(S):
Name: _____ Relationship: _____
Phone: _____

<https://citrinfoundation.org/>

TURN OVER



EMERGENCY CARD Citrin Foundation

I have a condition called: **CITRIN DEFICIENCY**
(CD: Inherited metabolic disorder)

IMPORTANT INFORMATION:

- **Please do not treat CD patient with high glucose infusion and GLYCEROL®.** There are no issues with general infusion to treat hypoglycemia, diarrhea, or vomiting, but in order to promote faster recovery, it is advisable to let patient consume what they wish after their appetite returns.
- **Avoid fasting** or prolonged periods without eating.
- Monitor for signs of **hyperammonemia** (elevated ammonia levels) and **hypoglycemia** (low blood sugar).
- Please be aware of **metabolic decompensation.**

<https://citrinfoundation.org/>

TURN OVER

Available to download and print from our patient website.

PARTNERSHIP WITH NATIONAL UREA CYCLE DISORDERS FOUNDATION (NUCDF)

The Foundation is delighted to announce a collaborative partnership with NUCDF. NUCDF is the driving force behind critical research to improve the understanding and management of urea cycle disorders (UCD), find new treatments, and ultimately a cure. NUCDF serves as a lifeline to UCD patients, families, and medical professionals worldwide seeking information, support, and HOPE.

PROFESSIONAL UPDATES

THE 72ND LINDAU NOBEL LAUREATE MEETING, JUN 2023

The prestigious Lindau Nobel Laureate Meetings are annual scientific conferences held in Lindau, Germany, since 1951 to bring together Nobel laureates and leading scientists around the globe to foster scientific exchange between different disciplines with over 600 participants. We are very pleased and honored to announce that Professor Sir John Walker, Chair of the Foundation's Scientific Supervisory Board, was one of the Nobel laureates to present at this year's physiology/medicine conference with a talk titled "Citrin Deficiency: A Defect in the Urea Cycle". The Foundation would like to express our utmost gratitude to Sir John Walker for his invaluable contribution in raising awareness of citrin deficiency and the Foundation at such a high profile international meeting. The full talk and abstract can be accessed [here](#).

SOCIETY FOR THE STUDY OF INBORN ERRORS OF METABOLISM (SSIEM) ARCHIBALD GARROD AWARD

We would like to extend our sincere congratulations to Dr. Jun Kido for receiving the prestigious Archibald Garrod Award from the SSIEM for his recent publication "Clinical manifestation and long-term outcome of citrin deficiency: Report from a nationwide study in Japan" Kido et al. *JIMD* 2022. Dr. Kido is the first Asian clinician scientist to receive this award. This highlights the wide-open field in citrin deficiency research where much can still be done. This also is a testimony to the outstanding work that Dr. Kido and the team at Kumamoto University have achieved under the leadership of Prof. Kimitoshi Nakamura, as well as a showcase of the successful collaboration between Kumamoto University and Prof. Johannes Häberle, who was also a meaningful co-author of the paper. You may find more information about the award [here](#).

CITRIN FOUNDATION STUDY ABROAD AWARD

Citrin Foundation is committed to supporting talented individuals dedicated to improving our understanding of citrin deficiency and the lives of those affected by the condition. To facilitate this, the Foundation has created the Citrin Foundation Study Abroad Award and we are pleased to announce Dr. Jun Kido (Kumamoto University) as the first recipient of this award for his exceptional clinical research contributions and dedication to citrin deficiency. This award grants Dr. Kido a unique opportunity to work exclusively on citrin deficiency research with Prof. Johannes Häberle at the University Children's Hospital Zürich for 8 months. We congratulate Dr. Kido for receiving this award and hope that more groundbreaking results will come from his research efforts.



GLOBAL CITRIN DEFICIENCY SYMPOSIUM



With the hope of reaching as many of our members as possible, we are excited to announce that the patient segment of the symposium taking place on **Wednesday, 20th September 2023** will be a **hybrid event**. This means that patients and families will have the opportunity to join us either in person or online. This innovative approach allows us to include a wider audience and facilitate meaningful interactions among professionals and patients around the globe.

We have curated an exciting program to provide our members with the opportunity to come together as a community. The patient segment will feature a range of sessions, including speeches from professionals, patient members and a dedicated Q&A session. For those joining in person, there will also be optional social activities held in the afternoon and evening.

If you are interested, please e-mail us at patients@citrinfoundation.org with your name and highlight whether you will be joining us in person or online. To ensure your participation, we kindly request you to **confirm your attendance by July 31st if you are attending in-person and August 15th if you will be attending online.**

Thank you for being a part of the Foundation's journey to finding a cure for citrin deficiency. We welcome suggestions on how we can improve our resources as well as ideas for new projects to explore and support you better. If you would like to get in touch, please email us at patients@citrinfoundation.org. We look forward to continuing to support you and your family.

You can look forward to the next edition of our newsletter in October.

<https://patient.citrinfoundation.org/en/>