

Supplement 1

5th International Meeting on Chronic Nonbacterial Osteomyelitis and Autoinflammatory Bone Disease

After a two-year delay, we are now happy to be able to host the first ever international Chronic Nonbacterial Osteomyelitis (CNO)/Chronic Recurrent Multifocal Osteomyelitis (CRMO) patient/family-driven research conference on May 25-26th, 2022 at the University of Liverpool, UK.

As part of this, we want to understand the key CNO/CRMO questions that you; the patients, and families see as the top priorities for getting some answers through research studies.

We have put together a few questions to collect this information from CNO/CRMO patients and families. The responses to the questions will then be used to set the agenda for the conference.

Please file one response per family. Children under 12 should complete the questionnaire together with a parent/carer.

You will be able to register your interest in attending the conference on our website www.EATC4Children.co.uk in the new year. Registration fees are waived for patients/parents but places are limited (and this does not include travel or accommodation costs).

Should you have any questions please email: laura.whitty@liverpool.ac.uk. We look forward to working together to better understand this rare disease.

* Required

1. Name

2. Are you a young person with CNO/CRMO or a parent/carer looking after a child (between the ages of 5-18) with this condition?

Mark only one oval.

Young person

Parent/Carer

3. How old are you/how old is your child?

4. Where do you live? *

Mark only one oval.

- UK/Ireland
- Continental Europe
- North America
- Central/South America
- Africa
- Asia
- Australia/New Zealand
- Prefer not to answer

5. Did you fill this survey in previously (Feb 2020)? *

Mark only one oval.

- Yes
- No

6. Are you happy to have your responses to this survey published in a manuscript summarizing patient and families needs? Your responses would be fully anonymised prior to publication. There would be no identifying information included. *

Mark only one oval.

- Yes
- No

7. How many years has it been since diagnosis?

8. How long did it take to receive a diagnosis?

9. Were you/your child (wrongly) diagnosed with another condition before the diagnosis CNO/CRMO was made?

Mark only one oval.

Yes

No

10. If you answered yes, what was the diagnosis?

11. Where are you/your child treated?

Mark only one oval.

Outpatient practice

Community hospital or health centre

Tertiary care centre (e.g. University Medical Centre)

Other: _____

12. Do you/your child have any other inflammatory symptoms/conditions?

Mark only one oval.

- Yes
 No

13. If you answered yes, which condition?

Mark only one oval.

- Palmoplantar pustulosis
 Psoriasis
 Inflammatory bowel disease (Crohn's disease or ulcerative colitis)
 Arthritis (joint inflammation)
 Other: _____

14. Please tick what medications you/your child is currently taking for CNO/CRMO? *

Check all that apply.

- NSAID (e.g. naproxen, ibuprofen, etc.)
 Corticosteroids (e.g. prednisolone, prednisone, etc.)
 TNF inhibitor (e.g. etanercept, adalimumab, infliximab, etc.)
 Bisphosphonate (e.g. pamidronate, zoledronic acid, etc.)
 Classical DMARD (methotrexate, sulfasalazine, etc.)
 Other: _____

15. What do you think is the biggest research priority for CNO/CRMO? (Please rank them - 1 being the highest priority) *

Mark only one oval per row.

	1	2	3	4	5
Investigations into the underlying causes of CNO/CRMO (Pathophysiology)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medication trials testing drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Studies into how the disease affects your mental and emotional wellbeing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding outcome measures that help us to treat patients more effectively in clinic and research studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Defining the ways we diagnose and classify CNO/CRMO	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. Is there a research question(s) you have about CNO/CRMO that you would like an answer to? *

17. What is your biggest concern about your/your child's CNO/CRMO? *

18. If you are UK based, would you be interested in attending a 2-day conference to learn about and discuss CNO/CRMO research? *

Mark only one oval.

- Yes
- No
- N/A

19. If you answered yes, would you be willing to share your/your family's story and experiences with CNO/CRMO at the conference (support would be provided to you)? *

Mark only one oval.

- Yes
- No
- N/A

20. Can we contact you about this? Please enter your email below.

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