

**Supplement 2**

# 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 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 clinicians. The responses to the questions will then be used to inform the agenda for the conference.

Please ensure that you complete this survey ONCE only.

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

**\* Required**

1. Name \*

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2. Institution \*

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## 3. 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

## 4. What is your sub-speciality? \*

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## 5. How long have you been practicing as a specialised rheumatologist? \*

*Mark only one oval.*

- 0-3 years
- 3-5 years
- 5-10 years
- Over 10 years

6. Do you work with adults or children? \*

*Mark only one oval.*

- Adults  
 Children  
 Both

7. How many CNO/CRMO patients do you diagnose per year? \*

\_\_\_\_\_

8. How many CNO/CRMO patients do you currently treat at your institution? \*

\_\_\_\_\_

9. Where do you treat your patients? \*

*Mark only one oval.*

- Outpatient practice  
 Community hospital or health centre  
 Tertiary care centre (e.g. University Medical Centre)  
 Other: \_\_\_\_\_

10. 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

11. How long would you estimate the average CNO/CRMO patient waits for a correct diagnosis after symptom onset? \*

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12. Were any of your patients (wrongly) diagnosed with another condition before the diagnosis CNO/CRMO was made? \*

*Mark only one oval.*

Yes

No

13. If you answered yes, what was the most common diagnosis?

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14. Do your patients have any other inflammatory symptoms/conditions? \*

*Mark only one oval.*

Yes

No

15. If you answered yes, which condition is most common?

*Mark only one oval.*

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

16. Please tick what medications you prescribe most commonly for CNO/CRMO? \*  
(Please rank by prescription frequency - 1 being most frequent)

*Mark only one oval per row.*

	1	2	3	4	5
<b>NSAID (e.g. naproxen, ibuprofen, etc.)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Corticosteroids (e.g. prednisolone, prednisone, etc.)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>TNF inhibitor (e.g. etanercept, adalimumab, infliximab, etc.)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Bisphosphonate (e.g. pamidronate, zoledronic acid, etc.)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Classical DMARD (methotrexate, sulfasalazine, etc.)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. 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
<b>Investigations into the underlying causes of CNO/CRMO (Pathophysiology)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Medication trials testing drugs</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Studies into how the disease affects your mental and emotional wellbeing</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Finding outcome measures that help us to treat patients more effectively in clinic and research studies</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Defining the ways we diagnose and classify CNO/CRMO</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. Is there a research question(s) you have about CNO/CRMO that you feel needs to be addressed? \*

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19. Would you be interested in attending a 2-day conference to discuss CNO/CRMO research? \*

*Mark only one oval.*

Yes

No

20. Can we contact you with further information about the conference? If so, please enter your email below. \*

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