



N°10



Jeudi 24 Novembre 2022

18h00-20h00

**Le M3C-Necker
Le Centre de référence des
Neutropénies chroniques
L'association Barth France**

M3C Academy

Syndrome de Barth

Webinar and live session - Read more by clicking below

www.carpedemm3c.com

www.neutropenie.fr

www.syndromedebarth.fr

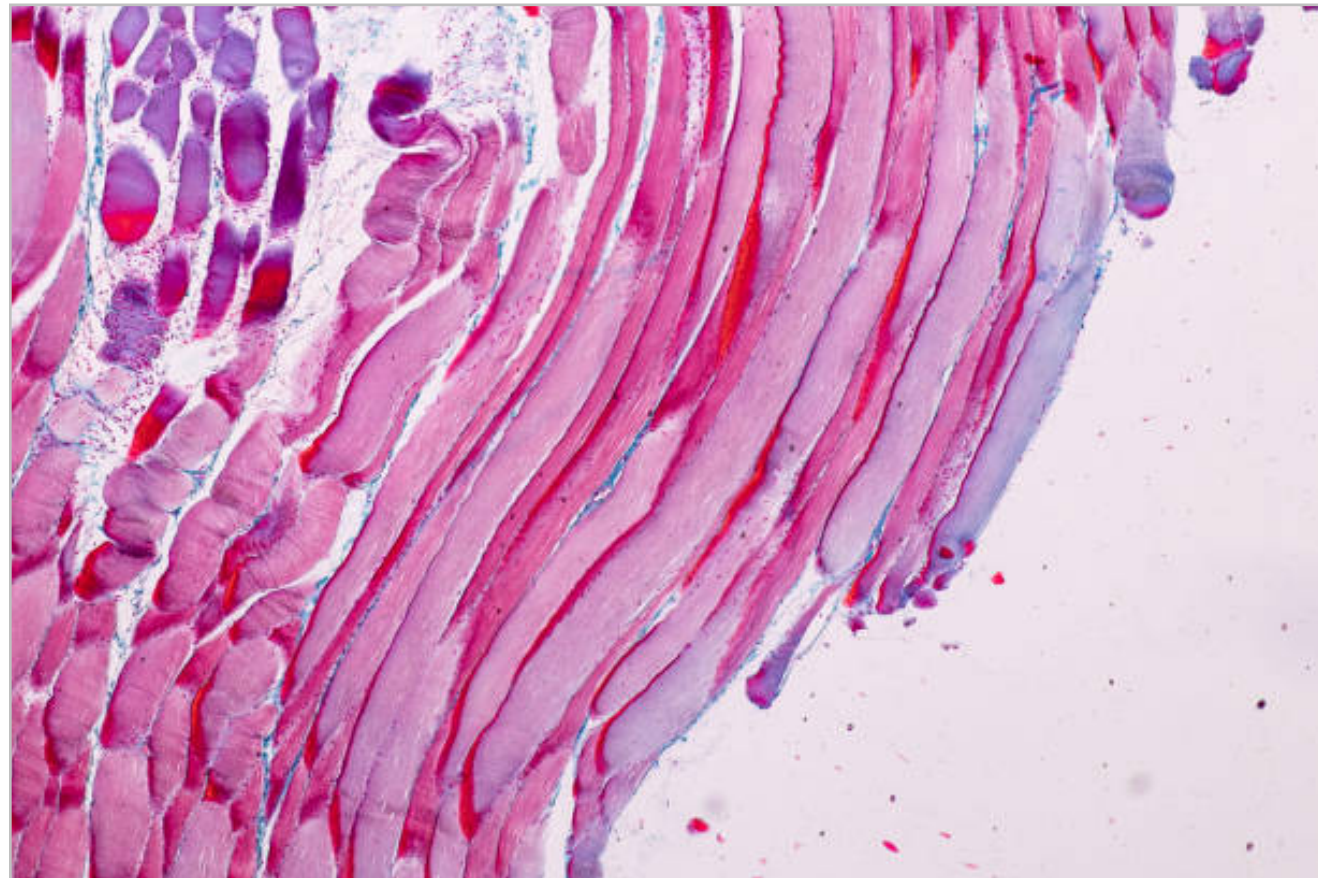
The M3C-Necker is organizing on a regular basis a Teaching course and Master Class named “M3C Academy” aiming to develop knowledge and skills in different congenital and pediatric cardiology topics.

This course/master class will take place at the Hôpital Necker Enfants malades six times per year. A webinar link will also be proposed for those who will not be able to attend the live sessions. Each topic will be scheduled as late afternoon/evening sessions.

The agenda of this teaching course will include :

1-Master class open to trainees and confirmed pediatric cardiologists, cardiac surgeons and potentially other specialists involved in the care of pediatric cardiac patients or adult congenital patients.

2-Update teaching course on the proposed topic with interactive discussions and analysis of “real-life” cases.



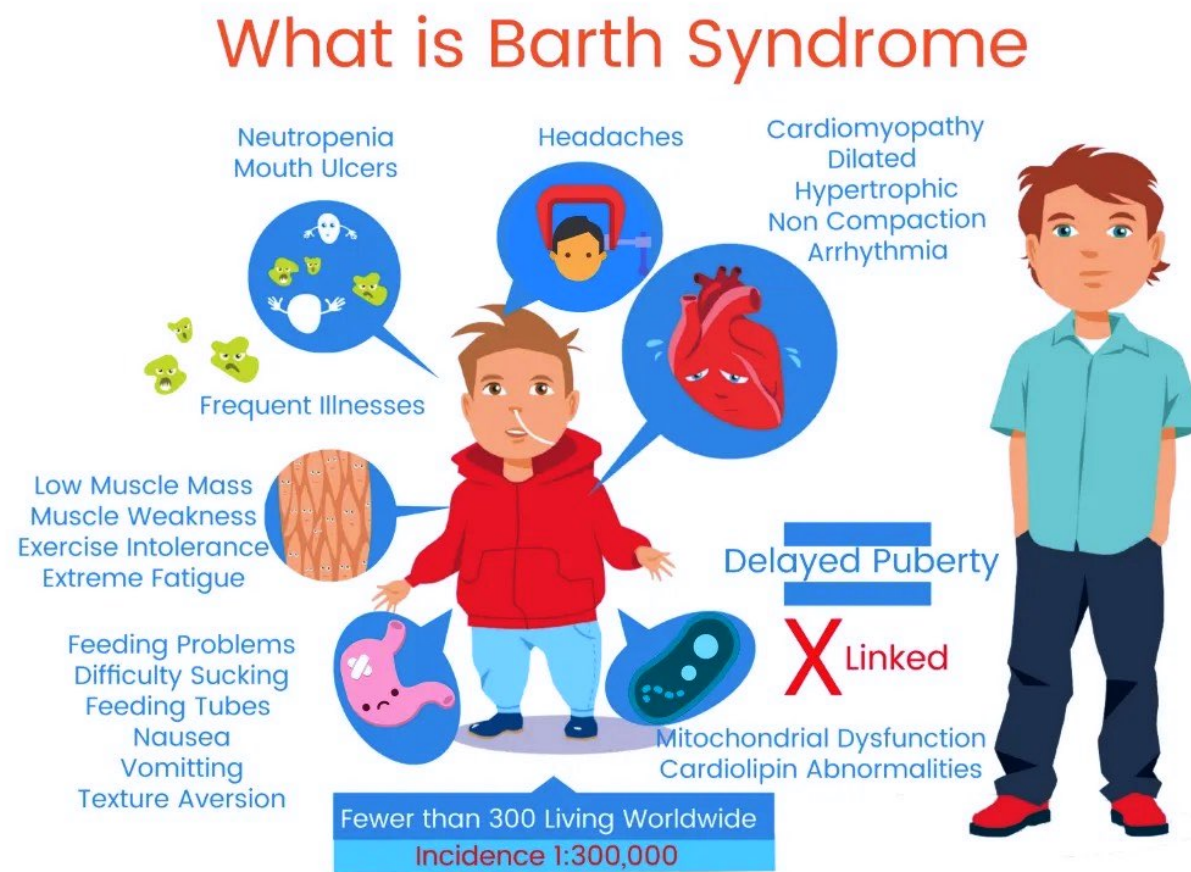
Congenital cardiology is a rapidly evolving field involving a complex multidisciplinary approach with a number of complementary medical and surgical strategies. Increasing knowledge is developing in a variety of domains including embryology, molecular genetics, integrative imaging, pharmacotherapy, structural cardiac interventions, electrophysiological optimisation of cardiac function, mechanical circulatory support and heart transplantation. Notwithstanding these technical progress and evolutions, the

importance of psycho-social support and care of patients and their families cannot be overstated. The above challenges and dynamics of new developments require guidance for core and advanced medical training in numerous fields of congenital and paediatric cardiology.

The Congenital Cardiology Unit of APHP-CUP hospital - M3C-Necker is the coordinating site for the “Malformations Cardiaques Congénitales Complexes-M3C” network.

Master Class

Le syndrome de Barth est une maladie d'une grande rareté liée à une mutation dans le gène de la tafazzine situé sur le chromosome X. Elle affecte les garçons et se manifeste par deux symptômes principaux qui sont une cardiomyopathie dilatée ayant quelques particularités phénotypiques et évolutives et une neutropénie chronique variable dans le temps exposant à des complications infectieuses. La physiopathologie est encore mal élucidée faisant intervenir les mitochondries et d'autres voies métaboliques. Il y a déjà 10 ans, le M3C-Necker, le CNR et Barth France avaient mené une étude ayant permis de caractériser une série de patients, de décrire leur évolution et de produire des recommandations françaises. Cet anniversaire nous conduit à renouveler cette enquête après une décennie afin d'avoir la suite de l'histoire pour les patients et les familles qui ont participé à la première étude. Nos objectifs sont d'affiner nos recommandations de diagnostic, de perfectionner notre prise en charge et de renforcer l'information autour de cette maladie très rare. Nous vous proposons donc une séance pluridisciplinaire de la M3C-Academy pour une mise au point sur le syndrome de Barth et comme kick-off de l'étude French-Barth-TYA.



From Barth France booklet

Master class en français et support en anglais

Update teaching course Barth syndrome



Heart failure



Genetics



Hematology



Quality of life

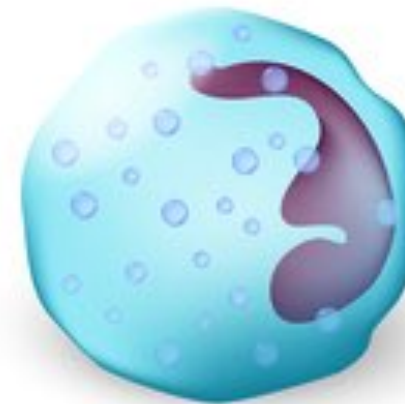


Survey

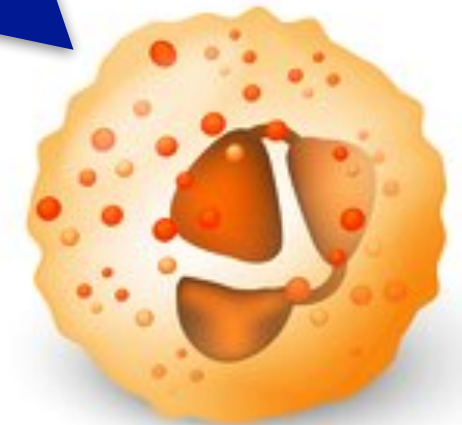
Lymphocyte



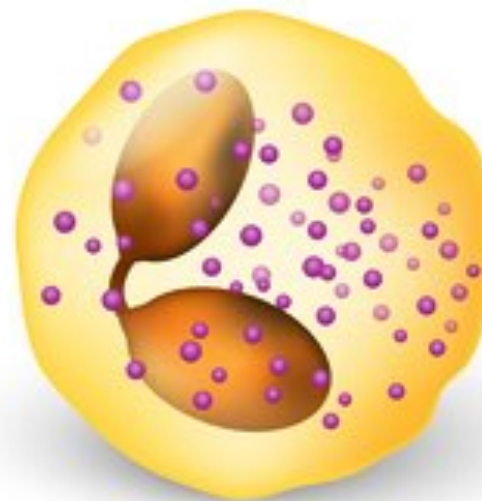
Basophil



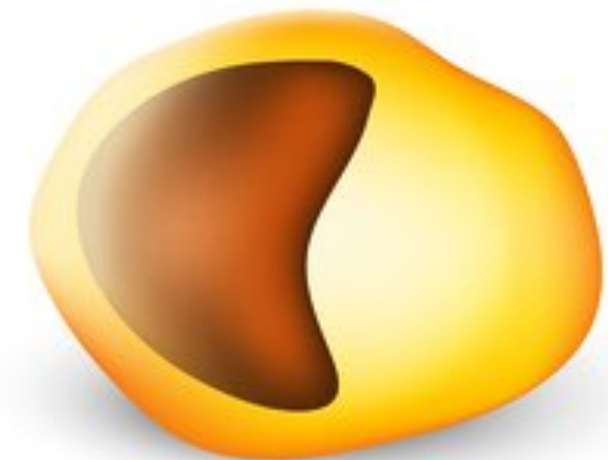
Neutrophil



Eosinophil



Monocyte



Program

Master Class

Barth syndrome

Thursday November 24th, 2022

6:00 pm-08:00 pm

Why is it an interesting topic ? - *Damien Bonnet*

Cardiomyopathy and other heart features of Barth syndrome - *Damien Bonnet, M3C-Necker*

Neutropenia and risk of infection - *Jean Donadieu, CNR*

The patient daily life - minor symptoms/high impact - *Florence Mannes, Barth France*

Synoptic presentation of French-BarthTYA - *Elena Panaioli, M3C-Necker*

8:00 pm: Farewell/Drink

M3C Academy sessions will be proposed live at the Congenital Cardiology Unit of Necker Enfants malades University hospital and a webinar access (via zoom) will be proposed for free to participants.

M3C academy sessions are free for FST-CPC students.

For other attendees, your support for our teaching activities to ARCFA is more than welcomed. You can access for free because it is our pleasure. But you are welcomed to pay for each session that you attend. Your contribution is encouraging and helps us to continue our masterclasses for the coming year.

For payment, you can contact Isabelle.descamps@aphp.fr. Thank you for your support.
For practical issues damien.bonnet1@gmail.com

