

NIH Clinical Center Grand Rounds, November 28, 2018

***Clinicopathologic Grand Rounds: Clinical Cases from the NIH Clinical Center
When "Lethal" Genetic Diseases of Infancy Are Diagnosed in Adulthood***

William Karkowsky, MD

Clinical Pulmonary/Critical Care Fellow, NHLBI/UMMC Research Track Program

Arlene Sirajuddin, MD

Staff Clinician, Advanced Cardiovascular Imaging Laboratory, NHLBI

Stefania Pittaluga, MD

Staff Clinician, Laboratory of Pathology, NCI

Kenneth N. Oliver, MD, MPH

Chief, Laboratory of Chronic Airway Infection and

Chief, Pulmonary Branch, NHLBI

Jennifer A. Kanakry, MD

Assistant Research Physician and Clinical Head,

Transplant, Experimental Transplantation and Immunology Branch;

Head, Neoplasms of Immunodeficiency Unit/NCI, Center for Cancer Research

Magdalena Walkiewicz, PhD

Molecular Genetics

NIAID Centralized Sequencing Initiative, NIAID

*One Continuing Medical Education (CME) credit will be offered for attending this lecture.

The Activity Code for this lecture is: 16589

To receive CME credit text the code to (443) 541-5052.

***Important Note: If you have not already done so, please be sure you have set up your profile with Johns Hopkins CME before you text the code. Please see below for detailed instructions.**

1. Register with the Johns Hopkins School of Medicine Office of CME at <https://hopkinscme.cloud-cme.com/aph.aspx>. You will provide your name, email address, and cell phone number. If you have attended a NIH CME activity in the past, and requested CME for your attendance, then your email address should be registered with Hopkins CME. ***Note:** The Hopkins CloudCME website is a third party website which is not managed by the NIH. The Johns Hopkins School of Medicine privacy policies will apply, and they have been reviewed and approved by the NIH Clinical Center Privacy Office. The Johns Hopkins Privacy Policy may be viewed at <http://www.hopkinscme.edu/migration/privacypolicy.html>.
2. Next text your email address to the Hopkins CME phone number, **(443) 541-5052**, which will pair your mobile phone with your Hopkins CME account that had been created/ used on past CME Self-Report Credit Forms. After you have attended, you will text the assigned "activity code" to the Hopkins CME phone number at (443) 541-5052 to receive CME credit. Once the text message is sent, your account is updated to reflect the CME credit earned.
3. If you have any questions on how to use the new CloudCME record keeping, please contact the Clinical Center's CME Coordinator, Mr. Kelechi Ezealaji, by email at rita.stevens@nih.gov or by phone at 301-435-6188.

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The NIH Clinical Center Grand Rounds is a Continuing Medical Education (CME) activity offered by the NIH Clinical Center Office of Clinical Research Training and Medical Education (OCRTME) with the Johns Hopkins School of Medicine as the CME provider.

Accreditation Statement

This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of Johns Hopkins University School of Medicine and the National Institutes of Health. The Johns Hopkins University School of Medicine is accredited by the ACCME to provide continuing medical education for physicians.

Credit Designation Statement

The Johns Hopkins University School of Medicine designates this Regularly Scheduled Series (RSS) CME Activity for 1 credit per session for a maximum of *42 AMA PRA Category 1 Credits™*. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Policy on Speaker and Provider Disclosure

It is the policy of The Johns Hopkins University School of Medicine and the NIH that the speaker and provider disclose real or apparent conflicts of interest relating to the topics of this educational activity, and also disclose discussions of unlabeled/unapproved uses of drugs or devices during their presentation(s). The Johns Hopkins University School of Medicine Office of Continuing Medical Education has established policies in place that will identify and resolve all conflicts of interest prior to this educational activity. Detailed disclosure will be made in the activity materials.

Speakers Name & Relationships

Relationship(s)

Michail Lionakis - CRADA Viamet Inc, Matinas Biopharma

No other planners have indicated that they have any financial interests or relationships with a commercial entity.

Non- FDA Approved or Off-Label Product Discussion

Baricitinib will be discussed.

For CME CREDIT TEXT CODE 16589 TO (443) 541-5052

*Please return completed evaluation form to folder in Lipsett or email to rita.stevens@nih.gov

*This form is optional and not required to receive CME credit. We greatly appreciate your feedback.

Speakers: William Karkowsky, MD, Arlene Sirajuddin, MD, Stefania Pittaluga, MD

Kenneth N. Oliver, MD, Jennifer A. Kanakry, MD, Magdalena Walkiewicz, PhD

Objectives:

- Discuss the clinical, radiographic and histological features of a rare autoinflammatory disease, CANDLE.
- Discuss disease pathogenesis and implications for treatment, and provide preliminary data from a compassionate treatment for CANDLE.
- Present the clinical phenotype of presumed “interferonopathies” and opportunities and challenges for diagnosis and future treatment

Please rate the attainment of objectives:

1. Define options and alternatives that will guide clinical practice:

1-Not at all 2-Very little 3-Moderately 4-Considerably 5-Completely

2. Evaluate practical information about clinical research principles based on state-of-the-art information about scientific discovery and clinical advances:

1-Not at all 2-Very little 3-Moderately 4-Considerably 5-Completely

3. Analyze information and opportunities to increase and improve collaboration between investigators:

1-Not at all 2-Very little 3-Moderately 4-Considerably 5-Completely

Please rate the overall effectiveness of the lecture(s):

4. The overall quality of the presentation(s) was:

1-Poor 2-Fair 3-Good 4- Very Good 5- Outstanding

5. How useful do you think the information that was presented is:

1-Not very useful 2-Somewhat useful 3-Moderately useful 4-Very useful 5-Extremely useful

6. To what extent did participation in this activity enhance your professional effectiveness:

1-Not at all 2-Slightly 3-Moderately 4-Greatly 5-Extremely

7. Will you change your practice in any way as a result of attending this activity:

1-Not at all 2-Slightly 3-Moderately 4-Greatly 5-Extremely

- What comments or suggestions do you have for the presenter(s):

- What suggestions do you have for future topics or speakers for Clinical Center Grand Rounds:

- Do you have any additional comments or suggestions to enhance the effectiveness of Clinical Center Grand Rounds:
