

HISTIOCYTOSIS  ASSOCIATION™
A Rare Community

[\(https://histio.org/\)](https://histio.org/)



eNewsletter

HISTIOCYTOSIS ASSOCIATION

-- Webinar Rundown--

HLH Research Webinar Recording



HLH Research: Progress and Importance, and the Role You can Play



Dr. Michael Jordan
Cincinnati Children's
Hospital Medical
Center.

Recording is now **live!**

Hosted by: Dr. Michael Jordan
and Dr. Ed Behrens



Dr. Ed Behrens
Children's Hospital of
Philadelphia

This past week we hosted the INTO-HLH Research Webinar with hosts Michael Jordan from Cincinnati Children's Medical Center and Ed Behrens from Children's Hospital of Philadelphia.

The recording for that is now up on our website and YouTube channel. Click below to view it.

View the recording
(<https://histio.org/resource-overview/webinars/>).

Upcoming Webinars in Transitional Care



A Rare Community



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PRESENT

**TRANSITION OF CARE FROM
PEDIATRIC TO ADULT - FAMILY TOOLKIT**

DECEMBER 14TH 1PM ET

ZOOM WEBINAR - REGISTRATION REQUIRED



ERIN SEIGH
Transition Coordinator
Parent Advocacy
Network



ANNIE SCHMIDT
Health Research &
Policy Associate
The National
Alliance to
Advance
Adolescent Health

Got Transition

In the next two months we will have webinars on transitional care.



First, on December 14th at 1pm we will be partnering with Got Transition for a webinar on their family toolkit and how it can help patients and families transition their histio care when aging out of Children's Hospitals.

The webinar will feature a special guest from the histio community and be hosted by Erin Seigh and Annie Schmidt from Got Transition.

There is no cost for registration, but it is required. Register below.

Register Here
(https://us02web.zoom.us/webinar/register/WN_GENGR1xhQ6WvtDxx5Qp-ug)

The graphic features a red and blue header with the text 'UNITE MATCH CARE' and 'Bridging the Gap of Bone Marrow Transplant Care'. Below this, it says 'Doctors! Join us in attending a free live webinar! Date of the webinar'. A circular photo of Sarah Rusch is shown with the caption 'Sarah Rusch Be the Match'. To the right, it says 'Hosted by:' followed by logos for the Leukemia & Lymphoma Society, Be The Match, and the Histiocytosis Association.

Bone Marrow Transplant Care

Then, on January 18th, 2024 the Association, Be The Match and the Leukemia and Lymphoma Society will all partner together on a webinar for transitioning care for Bone Marrow Transplant patients. The webinar will cover how to navigate a field which very recently had a lower survivorship, and thus, less transition care protocols in place.

Attendees will learn from patients and Physician Assistant Sara Rusch about best practices for transition care and how they can better advocate for themselves in the medical system as they or their family members transition to adulthood during BMT care.

There is no cost for registration, but it is required. Register below.

(<https://podcasters.spotify.com/pod/show/histio/episodes/Episode-001---Introduction-to-Beyond-the-Diagnosis-estelk>)

Register Here (https://us02web.zoom.us/webinar/register/WN_vLHo-PhJR3upsbiVSUHa-Q)

Mental Health for Patients and Caregivers Webinars





Finally, our friends over at the Erdheim [CI](#) mental health on November 16th. This 1

The recording for part 1 on caregivers c

page put on part 2 of their 2-part series in [ients](#).

[link below](#).

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http://www.instagram.com/histiocytosis_association

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(<http://www.youtube.com/histiocytosisassoc>)

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