

**General Body Meeting Minutes**

**Date: September 10, 2015**

**Start: 1301**

**Stop: 1356**

**FY15 NPAC Chair: CDR Anitra Johnson**  
**FY15 NPAC Executive Secretary: CDR Reginald Smith**

AGENDA TOPIC	DISCUSSION	FOLLOW-UP, RECOMMENDATIONS and ACTIONS	RESPONSIBLE PARTY
Opening Remarks: CDR Anitra Johnson	<ul style="list-style-type: none"> <li>□ Meeting called to order at 1301. Officers were reminded to press #5 to mute their phones.</li> </ul>		
Approval of April 20, 2015 and June 20, 2015 Minutes: CDR Anitra Johnson	<ul style="list-style-type: none"> <li>□ CDR Mary Brooks made a motion to accept both minutes.</li> <li>□ LCDR Tiffany Moore seconded the motion.</li> </ul>		
NPAC Presentation from NIH: "Undiagnosed Disease Program"- Captain Michele Nehrebecky	<ul style="list-style-type: none"> <li>□ CDR Casey Hadsall introduced CAPT Nehrebecky.</li> <li>□ CAPT Nehrebecky gave presentation; see attached.</li> </ul>		
CNO Remarks: RADM Trent-Adams	<ul style="list-style-type: none"> <li>□ The CNO thanked CDRs Johnson and Smith for their service during FY15.</li> <li>□ The CNO congratulated CDR Brooks on selection as incoming chair.</li> <li>□ The new site for OBC and OBC graduation is the Bolger Center in Potomac, MD.</li> <li>□ The Surgeon General has issued a new call to action titled "Walking and Walkable Communities" at the Kaiser Center. Numerous community partners attended the event. Walking was touted as doable, inexpensive and</li> </ul>		

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<p><b>NPAC Presentation from NOAA: "Providing Healthcare at Sea" - LCDR Randy A. Collins</b></p>	<ul style="list-style-type: none"> <li>□ useful to decrease diabetes and increase cardiovascular endurance.</li> <li>□ The 25<sup>th</sup> Anniversary of the Ryan White Care Act was celebrated at the White House. Jeanne White-Ginder attended the celebration, as well as Ryan White consumers and other stakeholders.</li> <li>□ The Nursing Category is not in the top categories for readiness. Nurse officers were reminded to make sure they are basic ready. Nurse officers were advised to prepare their folders for promotions. Direct Access will be down December 18, 2015 to January 4, 2016. Many items required for readiness will be inaccessible; officers are advised to get readiness and promotion items submitted expeditiously. The Direct Access migration will bring changes to pay and leave.</li> <li>□ CAPT Nehrebecky was thanked for her presentation.</li> <li>□ Call for new CNO has been announced. OSG will make the official announcement of the new CNO.</li> <li>□ The CNO is in transition to the position of DSG.</li> <li>□ RADM Clara Cobb retires on September 17, 2015.</li> </ul>		
	<ul style="list-style-type: none"> <li>□ CDR Reginald Smith introduced LCDR Randy Collins.</li> <li>□ LCDR Randy Collins gave the presentation; see attached.</li> </ul>		

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<p><b>Introduction of New Voting Members, Subcommittee Co-Chairs, NPAC Chair- CDR Anitra Johnson</b></p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> New Subcommittee Co-Chairs: Awards- CAPT Tessa Brown; Communications- LT Kelly Karr; Resource REACH- CDR Sidney Hairston and CDR Jaquin Jones; Readiness- CDR Stacy Barley</li> <li><input type="checkbox"/> FY16 NPAC Chair- CDR Mary Brooks; FY17 NPAC Chair Elect- CDR Reginald Smith</li> <li><input type="checkbox"/> FY16 NPAC Executive Secretary LCDR Keith Marin; FY17 NPAC Executive Secretary Elect- LCDR Reginald Smith</li> <li><input type="checkbox"/> New Voting Members: IHS- LCDR Jazz Fairjardo, BOP- CDR Derrick Gooch, DHS- CDR Gia Lawrence, NIH- CDR Margarita Velarde</li> </ul>	
<p><b>NPAC Chair Updates: CDR Anitra Johnson</b></p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> The COA Scientific Symposium will take place May 16-19, 2016 in Oklahoma City, OK. The theme is "Building a Better Tomorrow through Prevention Today."</li> <li><input type="checkbox"/> A clinical skills workgroup will be started in OCT. LT Janel Parham will lead the group of 7 officers. The goal is to establish a repository of resources where nurses can keep clinical skills up-to-date.</li> <li><input type="checkbox"/> CDR Mary Brooks: The Business and General Body meetings will continue on the first and third Mondays. The FY16 Mission Statement and Theme are forthcoming.</li> </ul>	

## My Journey as a PHS Nurse Officer

March 26, 2015  
CAPT Michele Nehrebecky, MS, CRNP

## 25 year path



- COSTEP
- NCI Inpatient Surgical Oncology
- Detail NIAID
- NCI Medical Oncology
- Acute Care NP
- Bethesda Naval Hospital
- Outpatient Medical Oncology
- Post Masters/FNP at USUHS

## NIH's Undiagnosed Disease Program (UDP)

NHGRI

## Program Announcement May 2008

- Began with 2 Nurse Practitioners (both PHS) and 1 scheduler
- Initial funding was \$280,000
- Budget increased to \$3.5 million per year
- NIH consultants



### UDP Goals

- To provide answers to patients with mysterious conditions that have long eluded diagnosis
- To discover new diseases that provide insight into human physiology and genetics

### UDP applicants

- Inquiries ~10,000
- Medical Records ~3000
- Acceptances ~750
  - 30% children
  - Seen by other services III
  - Roughly half are neurological
- Some diagnosis ~25%

### Types of Nurses in the UDP

- Research Nurses
  
- Nurse Practitioners

### UDP Operations

- Applicants submit medical records
- Referring physician sends summary letter
- UDP Director triages submitted records
- NIH senior consultants review records
- UDP Director synthesizes recommendations & makes final disposition
- Patients/referring physicians are informed by a standard letter
- Accepted patients come to NIH CC for 1 week

## Role of the NP

### Pre-admission

- Participate in patient screening for admission to the program
- Obtain detailed history
- Develop admission schedule with team input
- Pre-admission contact with family to identify family concerns and patient medical stability
- Assist with special travel needs
- Communicate and problem-solve issues with the team discovered as new records arrive and/or patient condition changes
- Present and modify admission plan as necessary

## Role of the NP

### During Admission

- Consent patients/families
- Perform History and Physical exam
- Daily exams and notes
- Perform some procedures during admissions
- Management of acute changes during admissions
- Wrap-up
- Education (Residents, NP students, GC students etc..)

## Multidisciplinary evaluation

- |                      |                           |
|----------------------|---------------------------|
| • Neurology          | • Allergy/Immunology      |
| • Ophthalmology      | • Oncology                |
| • Audiology          | • Hematology              |
| • Genetics           | • Dentistry               |
| • Gastroenterology   | • Rehabilitation Medicine |
| • Gynecology         | • Cardiology              |
| • Dermatology        | • Pain/Palliative Care    |
| • Rheumatology       | • Speech/Language         |
| • Infectious disease | • Pulmonary Medicine      |

## UDP in the Media

### Written press coverage

- *Newsweek* article
- Scores of newspaper articles
- *NY Times Magazine*, *People Magazine*

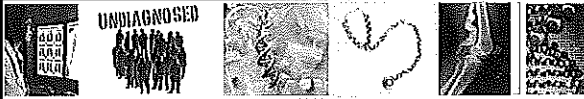
### Television and Radio

- NBC Nightly News
- Fox Television (NYC area); PBS
- CNN (Dr. Sanjay Gupta)
- ABC Today Show
- Discovery Health Channel
- 60 Minutes
- Anderson Cooper 360


## Publications

At least 40


- JAMA
- New England Journal of Medicine
- Science
- Genetics in medicine
- Nature Genetics



## The Undiagnosed Diseases Network



**NIH** National Institutes of Health  
Office of Strategic Coordination - The Common Fund

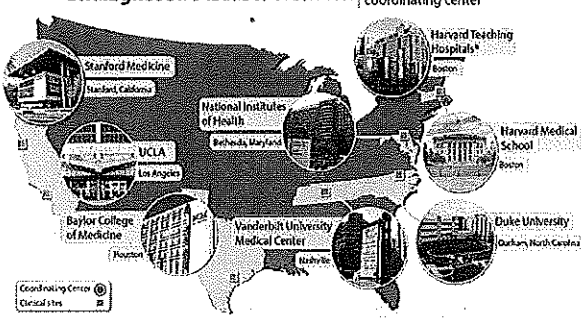


## Undiagnosed Diseases Network

- The NIH and the NIH's Common Fund announced that UDP has been expanded to become the Undiagnosed Diseases Network (UDN).
- July 1, 2014 - The NIH has awarded grants to six medical centers around the country to select from the most difficult-to-solve medical cases and together develop effective approaches to diagnose them.

### Undiagnosed Diseases Network


Seven clinical sites and a coordinating center



The NID site will continue to enroll about 150 patients per year; each of the clinical sites will ultimately enroll about 50 patients per year. A DNA sequencing core facility to be announced in the coming weeks.  
Boston Children's Hospital, Brigham and Women's Hospital and Massachusetts General Hospital participate in the Harvard Center for Sleep and Approaches to Neurogenetics and Autism.

**NIH** **UDN Objectives:**

1. Improve the level of diagnosis & care for patients with undiagnosed diseases
2. Create an integrated & collaborative research community to identify improved options for optimal patient management
3. Conduct clinical evaluation & scientific investigation in cases that involve patients with prolonged undiagnosed conditions
4. Each clinical site will contribute local medical expertise
5. Facilitate research into the etiology of undiagnosed diseases



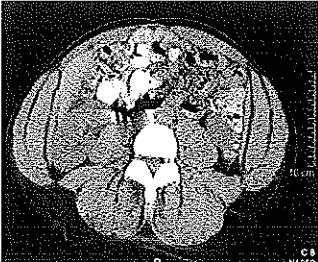
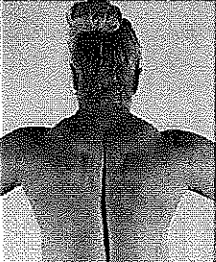
**UDN**

- enroll 1,400 patients across all of the seven clinical sites over the next four years
- \$145 million over 7 years

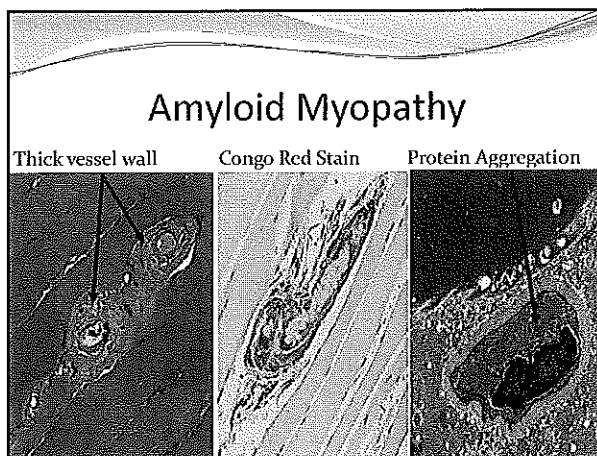
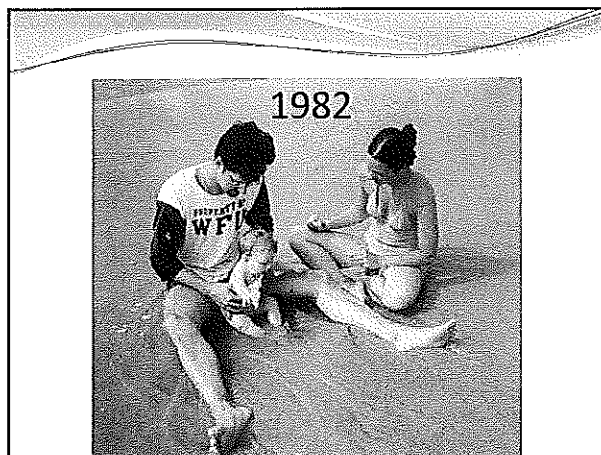
**Case Study**

**Muscle hypertrophy**

- No drugs
- normal growth hormone
- EMG myopathic
- normal initial muscle biopsy







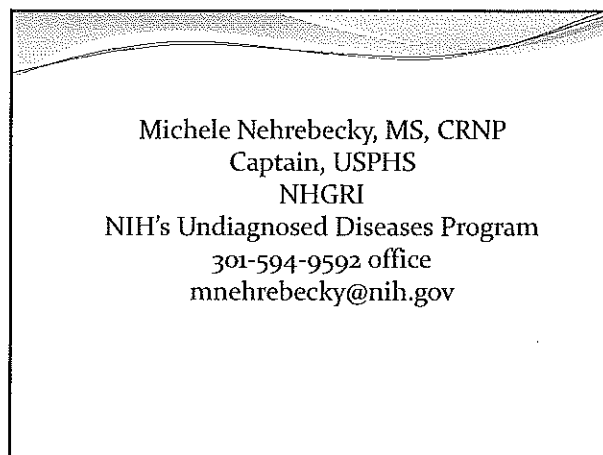
### Outcome

- Referred to Amyloid experts at Mayo Clinic
- Stem Cell Transplant in 6/2009
- Improvements within weeks
- Expect a full recovery

A black and white photograph of a woman with short, curly hair, wearing a light-colored tank top. She is sitting at a table and looking directly at the camera with a neutral expression.

### More Information

<http://rarediseases.info.nih.gov/undiagnosed>  
(866) 444-8806

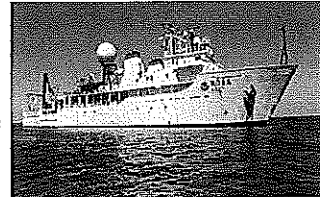


## Providing Health Care at Sea

LCDR Randy A. Collins, RN, BSN, BSB, ASCVT, USPHS  
Medical Officer  
NOAA Ship Okeanos Explorer  
randy.a.collins@noaa.gov

## Learning Objectives

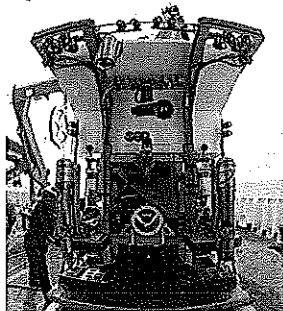
- Introduction to NOAA
- Introduction to NOAA Ships
- Introduction to *Okeanos Explorer*
- Introduction to Medical Officer aboard *Okeanos Explorer*



<http://oceanexplorer.noaa.gov/okeanos/about.html>

## USPHS RN, NP, or PA

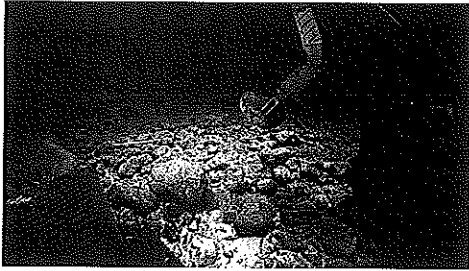
- Initiative
- Research
- Collaboration



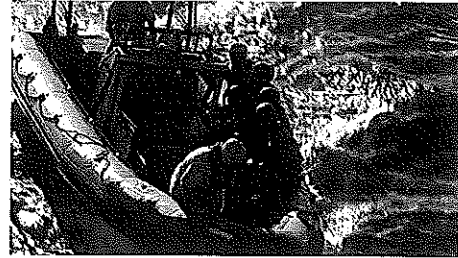
## Initiative



## Research



## Collaboration



## Nursing Leadership

- How do I, an RN, make a difference as the Medical Officer

