PKD Foundation – Centers of Excellence Program

HRA Members Meeting
October 6th, 2022

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Polycystic Kidney Disease

ADPKD, estimated to affect 600,000 Americans and 12.4 million worldwide, is the 4th leading cause of kidney failure.
"When I was diagnosed, my doctor told me to come back when my kidneys start to fail."
Management of ADPKD

**Diet**
Nutritional support
- Low osmolar diet
- High water intake
- Alkaline diet
- Keto diet

**Blood Pressure Control**
Role of primary care in early detection

**Rigorous target**
ACE/ARB

**Patients with advanced disease**

**Patients at risk for rapidly progressing disease**

**Tolvaptan**
Nephrologist guidance

**Transplant**
Dialysis PD/Hemo
Nephrectomy
Nephrology, transplant and urology support

Modified from Osama Amro, MD – Swedish Medical Center, with permission
Engaging stakeholders

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Clinicians

• What does excellent PKD care look like?

• What challenges are you experiencing?

• What could a valuable, centralized, national program look like?
What PKD clinicians told us:

▌ Biggest challenges:
▪ Management of patient needs as specialization increases
▪ Referral gap from both primary care and community nephrologists

▌ Needs
▪ Patient navigators
▪ Mentoring relationships with PKD experts
▪ Sharing of experience with case studies and new therapies
▪ Structure/guidance to facilitate shared care (specialist referral)
Engaging stakeholders

1. Clinicians
   - What does excellent PKD care look like?
   - What challenges are you experiencing?
   - What could a valuable, centralized, national program look like?

2. External Organizations
   - What are your COE program goals?
   - What barriers have you experienced?
   - What’s working?
What external organizations told us:

- COE designation programs are important as care become more specialty-based (e.g., as more therapies become available)

- Tiered system recommended, especially with considerations of training/motivating next “generation” of clinicians

- COEs need Partner Clinics (time limitations, waiting list) and vice versa (training, education)

External Organizations

- What are your COE program goals?
- What barriers have you experienced?
- What’s working?
Engaging stakeholders

1. Clinicians
   - What does excellent PKD care look like?
   - What challenges are you experiencing?
   - What could a valuable, centralized, national program look like?

2. External Organizations
   - What are your COE program goals?
   - What barriers have you experienced?
   - What’s working?

3. Patient Community
   - What does your PKD care look like?
   - What barriers are you experiencing?
   - Would this program solve any of these barriers for you or your family?
What PKD patients and caregivers told us:

• Patients see inconsistent care between family members receiving care at different clinics
• Access to and awareness of research opportunities is essential part of clinical care
• Simplifying the referral process would address a lot of barriers experienced in the clinic – a patient navigator could be a solution
• Cultivating Partner Clinics (community nephrologists in rural areas) had the most perceived value

Patient Community

• What does your PKD care look like?
• What barriers are you experiencing?
• Would this program solve any of these barriers for you or your family?
Why

• Improve patient care
• Means to understand clinical practice gaps, drive education and measure outcomes

What

• Program based on clinical expertise and research participation
• Commitment to participate in and provide education

How

• Criteria based selection with focus on a care team model
• PKDF financial support for Patient Navigator and health equity initiatives

Select clinical centers to drive improvement in PKD patient care and research excellence
COE care team construct

Patient Navigator (clinical and research support)

- Nephrologists PKD Specialist
- Primary Nephrologist
- Radiologist
- Geneticist
- Hepatologist
- Neurosurgeon
- Pain Team (multi-disciplinary)
- Transplant Surgeon
- Cardiologist
- Liver Surgeon
- Urologist
- Obstetrician (high risk preg specialization)
- Primary Care Physician
- Renal Dietician
- Psychologist/Psychiatrist
- Social Worker

- Nephrology specialist
- Diagnosis and assessment
- Extra-renal manifestations specialist
- General and follow-up care
COE Inception Conference

Goals:
• Present the program to the larger clinician community
• Encourage community to apply for the program
• Initiate the first annual meeting for the ADPKD COEs

Panelists:
• Provide feedback on not-yet final aspects of program
• Help create buy-in from the community – will this have an impact on barriers to care you experience in the clinic?
45 clinics applied for the program
Select the top two challenges that impact your clinic's service delivery

- Staffing Challenges
- Budget/ funding issues
- Patient outreach challenges
- Payer/insurance barriers or limitations
- Patient volume/ demand
- Lack of referral from primary care or...
- Wait time for patient visits
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Built-in elements of PKDF program!