2020 1st Qtr. Meeting:
ORV Transplant Coalition

02/18/2020
Agenda

2:30 – 3:15 – Best Practice Sharing
Enhanced Recovery Protocol for living donors and recipients
   Dr. Islam Ghoneim

3:15 – 3:30 – RadiANT Expansion Update
   Dr. Anne Huml

3:30 – 4:00 – Transplant Coalition Updates and Resource Review
   Dr. Anne Huml and Vicky Cash
Aims of RadiANT Study

- Characterize health center variation in access to early steps of the kidney transplantation process in larger region with support of ESRD Networks and transplant centers.

- Conduct epidemiologic analyses to understand the barriers/facilitators to early transplant access across different regions.

- Use early transplant steps as outcomes (or process measures) in interventions or quality improvement projects.
• Data Analysis to identify regional barriers/facilitators of transplant
• Focus groups of patients
• Surveys of providers

48 Transplant Centers
1,813 Medicare-certified Dialysis Facilities
~138,693 Patients*

*As of December 31, 2017, Source: CROWNWeb

IPRO Executive Leadership
President: Stuart Almer

ESRD Network 1
CT, MA, ME, NH, RI, VT
Director: Danielle Daley

ESRD Network 2
NY
Director: Sue Caponi

ESRD Network 6
GA, NC, SC
Director: Shannon Wright

ESRD Network 9
IN, OH, KY
Director: Victoria Cash
<table>
<thead>
<tr>
<th>Step</th>
<th>Responsible Party</th>
<th>Timeline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify IT person who will be contact for data submission</td>
<td>Each participating transplant center</td>
<td>By March 30th, 2020</td>
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<tr>
<td>Establish designated users for merged data</td>
<td>Each participating transplant center</td>
<td>By June 30, 2020</td>
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<tr>
<td>Reference forms/packet including:</td>
<td></td>
<td></td>
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<tr>
<td>* invoicing (format and contact)</td>
<td>Emory study team</td>
<td>By April, 2020</td>
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<tr>
<td>* legal language that CMS’s domain is for transplant centers</td>
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<tr>
<td>* example DUA</td>
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<td></td>
</tr>
<tr>
<td>* list of data elements to be included in query</td>
<td></td>
<td></td>
</tr>
<tr>
<td>* contacts at Emory for questions</td>
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<tr>
<td>Host webinar w/ IT person and Emory team to review data collection</td>
<td>Emory, NW 9, ORV Transplant Coalition</td>
<td>May 2020</td>
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<tr>
<td>forms for 1st data submission</td>
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<tr>
<td>* Include any tips/tricks from NW 2</td>
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<tr>
<td>Determine frequency of data submission (every 12 mo, 6 mo, more?)</td>
<td>NW 9 and ORV Transplant Coalition membership</td>
<td>After 1st data pull is collected- so, centers can gage workload</td>
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<tr>
<td>Determine if NW 9 and/or ORV Transplant Coalition want to hold</td>
<td>NW 9 and ORV Transplant Coalition membership</td>
<td>August, 2020</td>
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<tr>
<td>clinical meeting to review tablo reports generated— to brainstorm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ideas for QIP and research</td>
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</tbody>
</table>
### Estimated Timeline & Activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Year 1</th>
<th>Year 2</th>
<th>Year 3</th>
<th>Year 4</th>
<th>Year 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collection and linkage of patient-level referral and evaluation data across transplant centers (n=48) in Networks 1, 2, 6, and 9</td>
<td></td>
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<tr>
<td>Analysis of center-level variation in incidence rates of dialysis facility referral for transplantation, dialysis facility evaluation start, and transplant center waitlisting</td>
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<tr>
<td>Identify the patient-, neighborhood-, and health center-level barriers that explain disparities in early steps of kidney transplantation, and determine how barriers vary across geographic region.</td>
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<tr>
<td>Dialysis facility/transplant center survey data collection</td>
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<tr>
<td>Conduct dialysis patient focus groups</td>
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<tr>
<td>Dissemination of results to transplant centers, Networks, and dialysis facility stakeholders</td>
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</tbody>
</table>

**Goal: Start Data Collection in Early Summer 2020**
Frequently Asked Questions by Transplant Centers

• What will it cost my transplant center to participate?
  – There are no direct costs at this time, and we do not anticipate a cost for participating.
  – Our funding will support the data coordinating center at IPRO

• What is the benefit of participating?
  – There is $4,000 available for each transplant center participating
  – Transplant center feedback reports to help with outreach

• What information needs to be shared with the data coordinating center?
  – Patient identifiers (e.g., social security number, DOB), date of referral from a dialysis facility to a transplant center, and start of the transplant evaluation date

• I’m worried about the legal/regulatory issues with sending patient data – will we need to sign data use agreements with the data coordinating center?
  – ESRD Networks, as part of their CMS conditions of participation, have legal oversight of kidney patient data in your respective region, and they already have identifiers for patients with kidney disease. So no additional data use agreements are necessary if your ESRD Network is supporting the effort.
Division of Kidney Health

DKH will have programmatic and contract management oversight of the ESRD program while closely coordinating with transplant initiatives out of the Division of Strategic Innovation, Evaluation and Communication.
Foundation of ESRD Network Work

- HHS Secretary’s Priorities
- American Association of Kidney Patients
- 12TH SOW– NQIIC focus on Chronic Kidney Disease
- Executive Order to launch *Advancing American Kidney Health*
- ESRD Treatment Choices (ETC) Payment Model
- ESRD Treatment Choices (ETC) Kidney Transplant Learning Collaborative
Identify best practices offered by presenters on each LAN meeting.

Educate dialysis facility staff, patients, and family members.

Enlist patients, physicians and research leaders related to transplant to participate in the transplant initiative.

Fill the gap reported by dialysis facilities and transplant centers to track patient by the use of reports to both entities.

Encourage patients to list at more than one transplant center.

Champion and advance the transplant initiatives identified in the Executive Order on AAKH

Participate robustly in the ESRD Treatment Choices (ETC) Model Test Learning Collaborative

Utilize HCD and any available changes packages to further the transplant initiatives identified in the Executive Order of AAKH.

Support the work of the Transplant Learning Collaborative
Improve Transplant Coordination

- Identify high performers who have excelled educating patients/caregivers and communicating with transplant center to move patients to the waiting list and share best practices on LAN calls.

- Facilitate communication between hospitals, transplant centers, and nephrologists along with other healthcare providers to educate patients at the earliest diagnosis of ESRD about transplant.

- Utilize human centered design to identify successful interventions.

- Gather and utilize results oriented feedback to drive toward the goal.
Kidney Transplant Waitlist Growth

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Total Added</th>
<th>% Change</th>
<th>Growth</th>
<th>Growth Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Listings 7/1/14-6/30/15</td>
<td>35,566</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Listings 7/1/15-6/30/16</td>
<td>36,177</td>
<td>1.017179</td>
<td>0.017179</td>
<td>1.717933</td>
</tr>
<tr>
<td>New Listings 7/1/16-6/30/17</td>
<td>36,815</td>
<td>1.017636</td>
<td>0.017636</td>
<td>1.763551</td>
</tr>
<tr>
<td>New Listings 7/1/17-6/30/18</td>
<td>37,807</td>
<td>1.026946</td>
<td>0.026946</td>
<td>2.694554</td>
</tr>
<tr>
<td>New Listings 7/1/18-6/30/19</td>
<td>41,372</td>
<td>1.094295</td>
<td>0.094295</td>
<td>9.429471</td>
</tr>
</tbody>
</table>

Positive growth rate year over year with the largest rate of growth between 2018 and 2019.
Lessons Learned:
• Transplant Coalition is creating alignment with goal
• Focused Interviews helping to develop best practice models.
• Transplant Waitlist reports to facilities improved communications with transplant centers
• Monthly Goal and Participation Scorecards was valuable to engage facilities

CMS goal 2% improvement 323 patient
Achieved 220 or 68% of goal
NW waitlist ranking improved from 18th (last) to 12th
Increase the rate of patients on the Transplant Wait-list by 1.25%

- Last year 198 facilities did not put one patient on the waitlist.
- In 2019 NW9 had the lowest % of patients waitlisted in the country.
- NW9 put 1125 patients on the waitlist < 3% of our population.
- This year the Network will work with all the facilities in the NSA to add > 2000 patients to the waitlist.
C 4.2 Increased Rates of Patients on the Transplant Waiting list  OY4

Increase the rate of patients on the Transplant Wait-list by 1.25%

- Work with incident patients, prevalent patients, dialysis facilities, transplant centers and all other stakeholders

2020 QIA Plan –

- Integrate work of Transplant Coalition
- Increase communication between Transplant Centers, ESRD patients and facilities
  - Transplant center compare:
  - Determine best practices to overcome barriers in the 5 steps to transplant
- Provide education and develop educational materials for patients and facility staff
  - Benefits of transplantation
  - Kidney allocation
  - Kidney Donor Profile Index (KDPI)
  - Estimated Post-Transplant Survival Scores (EPTS)
  - Multiple listing
Current Projects

Subcommittees and Support from IPRO

• **Education Working Group**

  • Goal: Assemble a group of patient-facing educational materials about high KDPI, EPT scores, and CDC high risk donors which will improve patient education and increase patient consent to use of these organs as appropriate

  • **Tasks:**
    1. Work with IPRO and coalition leadership to share and help develop a universally agreed upon high-yield resource for each of the education topics that is at the appropriate level for patient use
    2. Understand how high risk/KDPI education and consent is carried out at the Transplant Center (percent of consent obtained, and when obtained)
    3. Develop model to improve consent levels ultimately improving use of organs and lowering discard rate.
A FRONT TO BACK 
LIST OF IDEAS TO 
SHORTEN YOUR WAIT

WHY LIVING DONATION?
Not only is living donation the fastest way to get a life-saving transplant, but live organs that are transplanted last longer and begin to function more quickly than deceased donations, allowing you to get back to living life to the fullest.

ITS A BIG ASK...
Many decide against exploring living donation as an option for transplant because it's uncomfortable to ask. But, there are resources available and people willing to help make that ask a little easier.

NO DIRECT ASK REQUIRED!
Transplant Center's can assist you with helping to toll your kidney story through social media campaigns. These campaigns are easy to set up and reach a large group of people. The more people who know about your need for a transplant the higher the chances that you will find a willing donor! Transplant Center's can also train someone to act on your behalf as a 'transplant champion,' who will help connect people in your community to your transplant story. Many patients have been successful finding a living donor using these methods and it can work for you, too!

WHAT IF MY LIVING DONOR IS NOT A MATCH?
No problem! Many transplant centers participate in a program called 'paired donation,' where you and your donor are matched with another kidney pair. Both recipients, one from each pair, receive a compatible living kidney donation. The paired donation program assures you receive a living donation; even when your willing donor is not a match to you. Make sure you check to see if this program is offered at your transplant center!
HELP YOUR PATIENTS WAIT LESS
For a Kidney Transplant

LESSENING THE WAIT

Patients on the transplant waiting list are monitored and checked regularly to ensure they have the most up-to-date information. This means that their condition cannot improve while waiting.

LIVING DONATION: MAKING THE ASK EASIER

Many patients and their families are unaware that they could save their lives by donating a kidney. If you or someone you know is in need of a kidney transplant, please consider donating.

DECEASED DONATION: THE ONLY OPTION? THERE'S STILL HOPE

Even if a potential donor is not a match for the patient, or if a living donor is unavailable, there are still options for saving a life. The network of transplant centers can work together to find the best match for the patient.

POTENTIAL DONOR NOT A MATCH?

THERE'S A HIGHER KPD NUMBER

If a living donor is not an option, or if the patient is not a match for a deceased donor, patients may still have options. The network of transplant centers can work together to find the best match for the patient.

DON'T RULE OUT KIDNEYS WITH A RISK FOR INFECTION

Many potential donors may be excluded due to past infections or medical conditions. However, a thorough medical evaluation may still be possible for some patients. The network of transplant centers can work together to find the best match for the patient.

ORGAN REGISTRY OF ANATOMICAL DONORS (ORAND)

The ORAND is the only national organ registry that tracks every organ from a deceased donor. This ensures that organs are allocated to the right patient, and that the patient receives the best possible care.
TRANSPLANT WORK-UP APPOINTMENTS CHECKLIST

This checklist includes a comprehensive list of tests and procedures that your transplant center may ask you to have to assess your overall health as part of your kidney transplant work-up process. You can use this checklist as a way to guide you through your work-up appointments. Please discuss with staff members at your transplant center if there are any different or additional tests or procedures that you need to complete for your evaluation; the team at your transplant center will help you arrange some of these appointments.

My Transplant center: ____________________________________________________________

Transplant center coordinator /contact information: ________________________________

My dialysis facility: ____________________________________________________________

My dialysis facility transplant coordinator /contact information: _____________________

Dialysis facility transplant coordinator /contact information: _________________________

<table>
<thead>
<tr>
<th>Is this Required? (3)</th>
<th>Transplant Work-Up Procedure/Test</th>
<th>Date of appointment</th>
<th>Appointment Completed? Check (3)</th>
<th>Did You Receive a Copy of Your Records or Clearance Letter? Check (3)</th>
</tr>
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<tbody>
<tr>
<td>Blood Work</td>
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<tr>
<td>comprehensive metabolic panel (CMP)</td>
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<tr>
<td>Cardiac</td>
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<tr>
<td>echocardiogram</td>
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<tr>
<td>electrocardiogram (EKG)</td>
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<tr>
<td>stress test</td>
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<tr>
<td>letter confirming cardiac clearance for surgery</td>
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<tr>
<td>Dental</td>
<td></td>
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<tr>
<td>routine dental exam</td>
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<tr>
<td>dental clearance for surgery</td>
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</table>

<table>
<thead>
<tr>
<th>Transplant Work-Up Procedure/Test</th>
<th>Date of appointment</th>
<th>Appointment Completed? Check (3)</th>
<th>Did You Receive a Copy of Your Records or Clearance Letter? Check (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaccines</td>
<td></td>
<td></td>
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<tr>
<td>hepatitis B</td>
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<tr>
<td>influenza</td>
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<tr>
<td>pneumococcal</td>
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<td></td>
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<tr>
<td>tetanus</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Other Tests</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>colonoscopy</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>mammogram</td>
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<td></td>
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<tr>
<td>pap smear</td>
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<tr>
<td>pulmonary function test (PFT)</td>
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<tr>
<td>prostate-specific antigen (PSA)</td>
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<tr>
<td>tuberculosis (PPD) test</td>
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Notes

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Additional Resources To Develop ???

Rate Most Helpful to Least

• 10-15 Minute Pod Cast presentation from each transplant center that covers evaluation and financial considerations

• Appointment Scheduling tracker

• Living Donor Resources
  • Building a Social Media Campaign toolkit
  • Donor educational resources
  • Financial guide for Donor
Current Projects

Subcommittees and Support from IPRO

• Communication Working Group
  • **Goal:** Create an easy method to share unique transplant center information about work up and eligibility requirements with ESRD facilities and patients.
  
  • **Tasks:**
    1. Collaborate to develop an accessible summary of program work up processes and eligibility requirements by transplant center for quick access and education with ESRD facilities and patients.
    2. Provide direction on standard content, display, maintenance of data accuracy and ways to optimize usability.
Transplant Center Compare
Web Based Portal

Unique program information for patients and staff to preview

- Consolidated information regarding all aspects of a particular transplant program
- Web based access
- Could be designed to select key factors in patient consideration and compare between 3 programs
- Update process needed to assure data stays accurate and up to date
11 dialysis facilities within 50 miles from the center of Lima, OH.

Choose up to 3 dialysis facilities to compare. So far you have none selected.

**Compare Now**

<table>
<thead>
<tr>
<th>Dialysis facility information</th>
<th>Quality of patient care star rating</th>
<th>Patient survey star rating</th>
<th>Distance</th>
<th>Shifts starting after 5PM</th>
<th>Peritoneal dialysis</th>
<th>Home hemodialysis training</th>
</tr>
</thead>
<tbody>
<tr>
<td>FRESENIUS KIDNEY CARE</td>
<td>★★★★★</td>
<td>★★★★</td>
<td>0.7 Miles</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**FRESENIUS KIDNEY CARE**
LIMA
750 W HIGH STREET, SUITE 100
LIMA, OH 45801
(419) 223-3391

In-center hemodialysis/ No. of stations: Yes/ 22
Transplant Selection Criteria - Recipient

Every transplant center has a list of criteria used to determine a person's eligibility for a transplant. Please review the chart provided, if you have one of the criteria listed in red the transplant center will not proceed with your work up. If you have conditions listed in yellow, then you will have to undergo additional testing and analysis before proceeding.

- Active Infection
- Severe Atherosclerosis
- Cardiac Disease
- Financial Barriers
- History of Cancer
- Undocumented Legal Status
- Cirrhosis Liver Disease
- Infection/Neurological deficit
- Physical Disability with Severe Imitation
- Lung Disease
- Tobacco Use
- Unstable Psychiatric Disease
- Uncorrectable Urological System

- Body Mass Index (BMI)
- Age
- Cancer
- Hepatitis B
- HIV
- Limited Life Expectancy
- Malnutrition
- Non-Compliance with Medical Treatment
- Substance Abuse
- Tuberculosis
- Vascular Risk Factors (PVD)
- Refusal to accept Blood or Blood Products

Transplant Center Criteria - Living Donor

Every transplant center provides a minimum health standard a potential organ donor must meet to be considered as a living donor candidate. Please review the list provided to determine if your identified donor meets the criteria outlined.

- Good Physical and Mental Health
- Must be 18 years of age or older
- Body Mass index (BMI) of <35

Must be free of the following:

- Uncontrolled High Blood Pressure
- Diabetes
- Cancer
- Hepatitis B
- Organ Disease
- Infectious Diseases

Additional Transplant Program Information for Consideration

<table>
<thead>
<tr>
<th>Average number of appointments needed to complete the transplant work up</th>
<th>What is the average amount of time patients wait for a transplant?</th>
<th>How many patients are put on the transplant waitlist by this center each month?</th>
<th>How many transplants does the center perform each year?</th>
<th>Does the transplant center have outreach facilities that may be closer to my home?</th>
<th>Can I refer myself to the transplant center for consideration?</th>
<th>What other transplant centers share the same list for kidneys? **</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 appointments</td>
<td>3 years, Dependent on blood type, see coordinator for additional information *</td>
<td>2 patients *</td>
<td>283 kidney transplants **</td>
<td>Yes, contact the coordinator for additional details</td>
<td>Yes</td>
<td>Cleveland Clinic</td>
</tr>
</tbody>
</table>

What Additional Support Programs does this Transplant Center Offer?

- Assistance with Scheduling work-up appointments
- Living Donor Support Social Media campaign/Champion program
- Pre-Work Up Transplant Education
- Parking Reimbursement or reduced rate parking
- Information and education on donor options i.e. living donation, donor registries & paired exchange
- Peer Mentors for support through process
- Free or low-cost housing for overnight procedures

*As reported by the Scientific Registry of Transplant Recipients 01/2020

** As reported by United Network for Organ Sharing
2020 Transplant Coalition Meetings

ORV Transplant Coalition, 2020

• 2020 ORV Transplant Coalition Proposed Meeting Dates:
  • 02/18/20 - 2:30 – 4pm (Webex) - Shared Best Practices
  • CHANGE 05/07/20 – 1-4pm – In Person Meeting Cincinnati, Ohio: Radiant Expansion change to
  • ****05/06/20 – 2 – 6 pm Cincinnati Ohio
  • 08/25/20 – 2:30 – 4pm (Webex)
  • 11/17/20 – 2:30 – 4pm (Webex)

Transplant Coalition Website
https://network9.esrd.ipro.org/transplant-coalition/
In Person ORV Transplant Coalition Meeting

* Tenative 05/06/20 2pm - 6pm

Draft Agenda

1. Review of Radient Expansion enrollment and data reporting
   - Education on next steps from Emory

2. Sharing Best Practices
   - Hepatitis C Panel discussion

3. ORV – Barrier #1 Education Update

4. ORV – Barrier #2 Communication Update

5. ORV – Barrier #3 Creating a Support System
   - Expert speaker on support systems in transplant
   - Discuss strategies to assist in building a support system
IPRO ESRD Network of the Ohio River Valley

New Contact Information

Network 9 is converting to a new E-mail service effective
Friday, February 14, 2020

We are releasing this flyer to help you
STAY CONNECTED!

New E-mail Addresses

<table>
<thead>
<tr>
<th>Name</th>
<th>Email</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Victoria Cash, Executive Director</td>
<td><a href="mailto:victoria.cash@ipro.us">victoria.cash@ipro.us</a></td>
<td>(216) 755-3051</td>
</tr>
<tr>
<td>Maria Johnson, Contract Coordinator</td>
<td><a href="mailto:maria.johnson@ipro.us">maria.johnson@ipro.us</a></td>
<td>(216) 755-3059</td>
</tr>
<tr>
<td>Andrea Bates, Patient Services Director</td>
<td><a href="mailto:andrea.bates@ipro.us">andrea.bates@ipro.us</a></td>
<td>(216) 755-3055</td>
</tr>
<tr>
<td>Laura Rodriguez-Carbone, Community Outreach Coordinator</td>
<td><a href="mailto:lara.rodriguez-carbone@ipro.us">lara.rodriguez-carbone@ipro.us</a></td>
<td>(216) 755-3056</td>
</tr>
<tr>
<td>Deb DeWalt, Quality Improvement Director</td>
<td><a href="mailto:deborah.dewalt@ipro.us">deborah.dewalt@ipro.us</a></td>
<td>(216) 755-3053</td>
</tr>
<tr>
<td>Sue Swan-Blohm, Quality Improvement Coordinator</td>
<td><a href="mailto:susan.swan-blohm@ipro.us">susan.swan-blohm@ipro.us</a></td>
<td>(216) 755-3054</td>
</tr>
<tr>
<td>Jerome Jemison, Sr. Data Coordinator/IT</td>
<td><a href="mailto:jerome.jemison@ipro.us">jerome.jemison@ipro.us</a></td>
<td>(216) 755-3057</td>
</tr>
<tr>
<td>Amar Patole, Data Analyst III</td>
<td><a href="mailto:amar.patole@ipro.us">amar.patole@ipro.us</a></td>
<td>(216) 755-3052</td>
</tr>
</tbody>
</table>
## Transplant Center Waitlist Report

### UNOS Transplant Waitlist Data by Transplant Center

**INIM - Indiana University Health**

Data as of: **07/2019**

<table>
<thead>
<tr>
<th>Patient Name n</th>
<th>DOD</th>
<th>Age</th>
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*Code 24: Patients are sometimes removed from the waitlist when the transplant center cannot contact them. If there is a date in this column, that is the status of this patient.

Print Date: **Tuesday, September 10, 2019**

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Next Steps

- **03/06/20** - Submit comments/suggestions to Wait Less Flyers and Transplant Center Compare
- **03/23/20** - Complete Radient Expansion enrollment survey
- **March 2020** - Transplant Center Report Release-Point person review and update records.
- **April 2020** – NW9 will initiate work on next identified resource
- **May 2020** – Attend May 6th In Person ORV Meeting