How to get the most out of your CF Center

Mary Helmers, R.N., B.S.N.
Pediatric CF Nurse Coordinator
CF Care Center
Lucile Packard Children’s Hospital
Who Does What

- Check in
  - Front desk staff
  - Insurance information/HIPAA

- Vital signs
  - Including height, weight, review meds

- Care team
Your Team

- Nurse coordinator
- Dietician
- Respiratory coordinator
- Social worker
- Patient service coordinator
- Research staff
- Your doctor
Mary Helmers

- Nurse coordinator
  - Ties your child’s care together
  - Education
  - Prescriptions
  - Running CF clinic
  - Phone advice
    - *NO live person*
    - Calls returned within 24 hours
  - Transition coordination
  - Monitor all test results
    - Labs, cultures, spirometry, x-rays....
  - Parent advisory board member

Contact Information: mhelmers@lpch.org
Phone: 650 736-1359
Julie Matel

- Dietician
  - Growth curve
  - Nutritional status
  - Diabetes education
  - Recommendation on enzyme dosing
  - Supplements
  - Tube feedings

Contact Information: jmatel@lpch.org
Phone: 650 736-0248
Kristin Shelton

- Respiratory coordinator
  - Therapy review
  - Spirometry
  - Sputum induction, sputum collection
  - Teaching new modalities
  - Equipment acquisition
Contact Information: kshelton@lpch.org
Phone: 650 724-0206
Lindsey Martins

- Social worker
  - Assess social situations
  - Coordinate assistance:
    - Financial
    - Counseling
    - Disability information
    - State assistance program
    - Mentoring

Contact Information: lmartins@lpch.org
Phone: 650 736-1905
Research staff

- Meet all newly diagnosed
- Consent for the CFF registry
- Identify eligibility for new studies
- Coordinate lab samples
- Continuity between both adult and pedi programs
- Plan education days

Contact Information: cedunn@stanford.edu
Phone: 650 736-0388
Miguel Huerta

- Patient Services Coordinator
  - Initial contact for all new patients
  - Schedules all new patients
  - Authorization for testing, visits, prescriptions
    - Contact him with insurance changes, ASAP
  - Mails out sputum and lab results
  - Assists the nurse coordinator
Contact Information: mhuerta@lpch.org
Phone: 650 498-2655
FAX: 650 724-6400
Your CF Doctor

● The CF expert
  – Additionally you may see…
    ● Medical student
    ● Resident
    ● Fellow
  – Contacting your doctor:
    Please call Mary at 650 736-1359
Goal of Care Coordination

Proactive prevention of CF symptoms through...
Your Child’s Care

- Quarterly clinic visits
- Sick visits
- In-depth yearly visit  
  ● Done on birth date
- Transition  
  ● Booklets handed out at age 8
Quarterly Visits

- Proactive Prevention
- Watching for early CF related symptoms
- Medications & refills
- Flu & other vaccines as needed
- Education as needed
Sick calls – What we need to know

The Cystic Fibrosis Center at Stanford

Please leave the answers to this simple checklist on our voicemail when you call.

Include the questions on allergies, treatments, pharmacy, meds, and how to reach you.

CHECK FIRST

• Feeling sick?
• Concerned about your child?
• Have a question for the nurse?
• Need prescription refills?

Things to check before you call the CF Center

TEMPERATURE

✓ Current temperature
✓ Medications taken
✓ Time meds taken

COUGH

✓ Frequency
✓ Productive
✓ Non-productive

APPETITE

✓ Good
✓ Fair
✓ Poor

ABDOMINAL PAIN

✓ Taking enzymes
✓ Stools float or sink
✓ Last bowel movement

WEIGHT LOSS

✓ Yes
✓ No

SPUTUM

✓ Color
✓ Consistency
✓ Amount

HEADACHE

✓ Sinus pain
✓ Nasal congestion
✓ Nasal discharge: color

ENERGY LEVEL

✓ Normal
✓ Low
In-Depth Yearly Clinic Visit:

- Review medications & refills
- Annual Labs
- Chest X ray
- CF-related diabetes (OGTT)
  - Age 6
- Bone disease (DEXA scan)
  - Age 16
- PFT’s
  - Age 6
- Education review
Additional Needs, PRN

- Phone Advice
- Follow-up
- Medications refills
- Home care management
- Labs & tests results
- Hospital & clinic communication
- Collaborates with adult coordinators
Transition

- Ongoing process
- Booklets
- Individual plan
  - 18-21 years
- Hospital transition
  - Team role
- Quarterly transition meetings