Transitioning from Pediatric to Adult Rheumatology

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Pediatric Rheumatology

UW Medicine
School of Medicine
Overview

1. Evidence for the Need for Transition Support
   a. Long-term outcomes: JDM, SLE, JIA
   b. Provider, health care system and patient factors affecting transition

2. Historical Perspective

3. ACR/ACP/AF Pediatric to Adult Health Care Transitions Initiative
   a. Resources: Transition Toolkits

4. Defining transition success: Outcomes measurement
Limb Pain in a Toddler

- 6 weeks of right knee swelling
- Cannot straighten knee
- Fully active
- Limps more in morning
- Ibuprofen helps a little
Transition in JDM: Is it important?

• Do JDM patients need ongoing care into adulthood?
• What is the risk of ongoing disease activity?
• What is the risk of ongoing disease-related damage?
Long-term outcomes in JDM

Before 1960:
• 1/3 died of disease-related causes
• 1/3 severely disabled
• 1/3 recovered without severe disability

2014:
• Mortality <2%
• Ongoing disease activity
• Calcifications
• Contractures
Long-term outcomes in JDM

- 65 Canadians a median 7.2 years after diagnosis (3-14y)
- Median age at diagnosis 5.8 years (1 to 16y)
- Ongoing disease activity common
  - 40% rash
  - 10% reported weakness
  - 22% reported pain
  - 35% remained on medication

- One death

Huber A&R 2000
Long-term outcomes in JDM

Disability according to Childhood Health Assessment Questionnaire (N=65)

- None: 72%
- Mild: 20%
- Moderate to severe: 8%

Huber A&R 2000
Long-term outcomes in JDM

- 60 Norwegian JDM patients (4 had died)
- Median f/u time 16.8 years (2 to 38)
- 65% age ≥ 18 years at f/u
- 90% had disease-related damage (MDI < 1)
- 61% had active disease with DAS ≥ 3 (0-20)
- Follow up time correlated with damage
- 36% reported some disability (HAQ > 0)
Long-term outcomes in JDM

Other autoimmune diseases in 15% (N=9)

• Hypothyroidism (N=3)
• Psoriasis (N=3)
• Celiac disease (N=2)
• Hyperparathyroidism (N=1)
• Dermatitis herpetiformis (N=1)
• Uveitis (N=1)

Sanner Rheumatology 2009
Do JDM patients need adult care?

• For most patients... YES
  • Ongoing disease activity
  • Continue to accrue disease damage
  • Continuing need for immunosuppression
  • Risk of additional autoimmune processes
Outcome of JIA
Start of 21\textsuperscript{st} Century

• Majority of children continue to have active disease into adulthood
• Joint damage frequently occurs
  • greatest in the first 2 years of disease
• 44% achieve remission
  • by 2 yrs off of meds most have flared
  • <10% are successfully off meds > 5 years
20th c. JIA: Mostly Active Disease
N=437 Follow up: 4 – 22 years (median 6.5)


% Time Spent with Active Disease

- Oligo
- Ext. Oligo
- RF+ Poly
- RF- Poly
- Systemic

Active disease
Remission
Childhood-onset SLE associated with an *increased mortality* risk (HR: 3.1; 95% CI: 1.3-7.3)

- Lower *socioeconomic* status measured by education (HR: 1.9; 95% CI 1.1-3.2)
- *End stage renal disease* (HR: 2.1; 95% CI 1.1-4.0)
Transition in Rheumatology: How are we doing?

• National Survey of Children with Special Health Care Needs
• Only 50% of teens with JIA reported discussing transition-related issues with their doctor
• 23% had discussed insurance coverage
• 19% had discussed transfer to adult provider
• 24-28% did not feel well-informed, know how to handle a flare, or felt involved in decision-making

Scal, 2009
Stringer 2015 Pediatric Rheumatology
# Childhood-Onset SLE Disease Activity and Transition Outcomes

## Table 3: Transition outcomes

<table>
<thead>
<tr>
<th>Transition Outcome</th>
<th>Participants (N = 50)</th>
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<tbody>
<tr>
<td></td>
<td>N, (%) or Mean ± SD (Range)</td>
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<tr>
<td>Days from last pediatric to first adult provider visit</td>
<td>253 ± 392 (6–2017)</td>
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<tr>
<td>Patients with ≥ 1 gap in care during PTP</td>
<td>36 (72%)</td>
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<tr>
<td>Admissions per year of PTP (n, mean LOS\textsuperscript{b} in days ± SD)</td>
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<tr>
<td>Year 1</td>
<td>22, 8.79 ± 12.5</td>
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<tr>
<td>Year 2</td>
<td>22, 4.07 ± 4.7</td>
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<tr>
<td>Year 3</td>
<td>17, 3.82 ± 1.8</td>
</tr>
<tr>
<td>Number of patients admitted during PTP</td>
<td>15 (30%)</td>
</tr>
<tr>
<td>ED visits per patient during PTP (mean ± SD, median, range)</td>
<td>1.9 ± 5.2, 0 (0–34)</td>
</tr>
<tr>
<td>% Missed appointments in LC/total LC\textsuperscript{c} appointments per person (mean ± SD, median, range)</td>
<td>9.2% ± 13.5, 0 (0–55%)</td>
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<tr>
<td>Patients with ≥ 2 missed appointments during PTP</td>
<td>16 (32%)</td>
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\textsuperscript{a}PTP: post-transition period.
\textsuperscript{b}LOS: length of stay.
\textsuperscript{c}LC: lupus center.

Son 2016 Lupus
### Are Young Adults with Rheumatic Disease Getting to Adult Care?

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Country</th>
<th>N</th>
<th>Successful Transfer (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jensen</td>
<td>2015</td>
<td>US</td>
<td>210</td>
<td>42%</td>
</tr>
<tr>
<td>Chanchlani</td>
<td>2015</td>
<td>UK</td>
<td>152</td>
<td>43%</td>
</tr>
<tr>
<td>Hazel</td>
<td>2010</td>
<td>Canada</td>
<td>100</td>
<td>48%</td>
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</table>
2015 “I really consider myself one of the lucky ones”
Transfer from pediatric to adult rheumatology care is one of MANY simultaneous transitions

- High school to college or work
- Parents’ home to independent living
- Romantic relationships
- New primary care physician
- May move to new part of the state or country
- Insurance coverage
Children with government-sponsored insurance (i.e. Medicaid) are at risk for losing coverage after age 18.

• Different in every state and county.
• Other potential options:
  • Parent’s plan
  • University-sponsored plan
  • Employer-sponsored plan
Understanding Teenagers
YES, YOUR TEEN IS CRAZY!
Loving Your Kid Without Losing Your Mind

MICHAEL J. BRADLEY, Ed.D.
Where’s the Gap?

Pediatric Rheumatologists

• Not enough adult providers to take young adult patients
• No payment for transition preparation
• Not informed about community support services
• Hard to break the patient/provider bond
• Poor communication with adult providers

Adult Rheumatologists

• Lack of training in adolescent health and childhood-onset chronic illness
• Poor communication with pediatric providers
• Insurance barriers (loss of coverage, poor Medicaid reimbursement)
• Staff not trained to interact with young adults
Historical Perspective

• 1970s-1980s: Improving survival in childhood-onset conditions
• 1980s: Interest in integrating disabled youth into the community
• 1990: First publication on transitioning youth with chronic conditions to adult care
Historical Perspective: We have a plan....

• 1996: First transition guidelines published in Pediatrics

“Planning is essential to achieve appropriate transition from pediatric to adult health care... the pediatrician should actively participate in the process.”

*Principles:*

• Begin early
• Patient & family engagement
• Co-management
Health Care Transition: A Policy Priority

- Recognized as an “essential service” in the Affordable Care Act
- Healthy People 2020 includes transition planning as a goal
- Maternal and Child Health Bureau named transition as 1 of 15 national performance measures for Title V
- 32 state public health agencies selected transition as a performance measure priority
Interventions can improve rheumatology transfers

• US transition intervention improved rates of successful transfer to adult rheumatology care (Rettig 1991)

• UK JIA transition intervention improved likelihood of creating a transition plan and attendance at adult visits (Robertson 2006)
What Health Care Skills Do Teens Need to Learn?

- Know medical history & keep records
- Know medications and take them reliably
- Fill prescriptions
- Know when to go to the lab or eye doctor
- Make medical appointments
- Be familiar with health insurance
- Know signs of flare and when to call the doctor
- Be his/her own advocate
Transition Resources
Providers want explicit practice approaches and tools.

Core concept: youth needs to experience an adult model of care prior to transfer.

Federally funded National Health Care Transition Center.

GotTransition.org
Got Transition aims to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.
Six Core Elements of Health Care Transition

1. Transition Policy
2. Tracking and Monitoring
3. Transition Readiness/Self Care Assessment
4. Transition Planning
5. Transfer of Care/Initial Adult Provider Visit
6. Transition Completion/ongoing care/Consumer Feedback
American College of Physicians
Council of Subspecialty Societies

Pediatric to Adult Health Care Transitions Initiative
Specialty Societies Represented
Specialty Societies Represented
Pediatric to Adult Rheumatology Care Transition

Transitioning patients with childhood-onset rheumatic diseases that persist into adulthood can be complex and challenging. The ACR has developed a toolkit to assist in the transition of young adults phasing out of their pediatric rheumatologists practice to an adult rheumatologist. These toolkits focus on two diseases: Juvenile Idiopathic Arthritis and Lupus.

The ACR transition toolkits are split into two groups: Information/Toolkit for Pediatric Rheumatologists and Information/Toolkit for Adult Rheumatologists.
ACR/ACP Pediatric to Adult Rheumatology Transition Resources: JIA and SLE

**Pediatric Rheumatology**
- Transition Policy
- Transfer Letter
- Medical Summary Juvenile Idiopathic Arthritis
- Medical Summary Lupus
- Transition Readiness Assessment Questionnaire (TRAQ)
- Transition Readiness Assessment for Youth (GotTransition)

**Adult Rheumatology**
- Patient Welcome Letter
- Patient Self Assessment
- Five Things to Know About Lupus
- Five Things to Know About Juvenile Idiopathic Arthritis
- Medical Summary Juvenile Idiopathic Arthritis
- Medical Summary Lupus
We want to help our patients make a smooth transition from child-centered care to adult health care. This means we will work with teens and young adults and their families to help them prepare for adult health care. This process may start at age [insert age for practice] years. In child-centered health care, parents make most of the decisions. In adult health care, the young adult is the decision maker. To help get ready for adult care, we will spend time during some visits with the teen without the parent present. This allows teens to become more independent with their own health care.

Teens become legal adults at age 18 years. Many of our young adult patients still want their family members to help make health care decisions. We encourage this family support. In order for us to share health information with family members, the young adult needs to give us permission. Some young adults are not able to make health care decisions. In that case, we help families to legally make decisions for the young adult.

We will help young adults and their families decide on the age to change to an adult provider. The best age to switch to adult care will be different from person to person. Usually this change will occur by the age of [insert age range for practice] years. We will help with selecting an adult provider and sending medical records.
Dear [Adult Provider],

[Name] is an [age] year old patient followed in our pediatric rheumatology practice who will be transferring to your care. This patient’s first appointment with you is scheduled on [date]. [His or her] primary rheumatologic diagnosis is [diagnosis] and other important medical concerns include [list concerns]. You also may want to know that [insert interesting personal detail to help adult rheumatologist engage with young adult]. Enclosed please find a medical summary and other pertinent records.

I have followed [name] as a patient since age [age] and am very familiar with [his or her] rheumatologic history. I am happy to provide you with any consultation assistance during the initial phases of [name’s] transfer to adult care. Please do not hesitate to contact me by calling [phone] if you have further questions.

Anticipated complexity of this transfer to adult care:

- Low complexity
- Moderate complexity, specific concerns: ____________________________________________________________
- High complexity, specific concerns: ____________________________________________________________

This transfer package includes:

- Transfer letter
- Medical summary
- Guardianship or health proxy documents if indicated
- Fact sheet about condition
- Additional records

Thank you very much for your willingness to assume the care of [name].
An Adult Rheumatologist Needs to Know About a Patient With Pediatric Onset Lupus

1. One in five patients with lupus is diagnosed in childhood or adolescence.

2. Pediatric onset lupus is more aggressive compared to adult onset lupus. Children and adolescents with lupus tend to have more widespread and severe organ involvement. Compared to adult onset SLE, children and adolescents with SLE are more likely to have CNS and renal involvement, to develop end stage renal disease, and to be hospitalized for lupus. In addition, patients with pediatric onset SLE have consistently higher disease activity and accrue more SLE-related damage than those with adult-onset SLE. Patients with pediatric onset lupus are susceptible to macrophage activation syndrome, a “cytokine storm” characterized by fever, disseminated intravascular coagulation, and end organ dysfunction.

3. Pediatric onset lupus has higher mortality compared to adult onset lupus. Even despite having fewer co-morbidities than their adult counterparts, adolescents with SLE have a two-fold higher mortality rate.

4. Long term complications of lupus and its treatment start in childhood and adolescence. Surrogate markers of atherosclerosis such as carotid intima medial thickening are already present in adolescents with lupus. Low bone mass can also develop early and because peak bone mass is achieved in the teen years, adolescents and young adults with lupus are at particular risk for poor bone health. Thus efforts to prevent or treat hypertension, dyslipidemia, low bone mass may need to begin early. Because lupus and its treatment increase risk of infection, it is important to keep preventive vaccines updated according to guidelines.

5. Teens and young adults are often not ready to care for themselves. Teens and young adults may not yet have well-developed self-management and self-advocacy skills. This can translate into missed appointments and non-adherence to treatment, requiring steady patience and support on the part of the health care team. Particular guidance may be required with respect to reproductive health, substance use (including interaction with medications), and lifestyle choices which minimize the effect of longstanding arthritis on cardiovascular risk.
**Transition Readiness Assessment Questionnaire (TRAQ)**

**Directions to Youth and Young Adults:** Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

<table>
<thead>
<tr>
<th>No, I do not know how</th>
<th>No, but I want to learn</th>
<th>No, but I am learning to do this</th>
<th>Yes, I have started doing this</th>
<th>Yes, I always do this when I need to</th>
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<tr>
<td><strong>Managing Medications</strong></td>
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<tr>
<td>1. Do you fill a prescription if you need to?</td>
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<tr>
<td>2. Do you know what to do if you are having a bad reaction to your medications?</td>
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<tr>
<td>3. Do you take medications correctly and on your own?</td>
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<td>4. Do you reorder medications before they run out?</td>
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<tr>
<td><strong>Appointment Keeping</strong></td>
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<tr>
<td>5. Do you call the doctor’s office to make an appointment?</td>
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<tr>
<td>6. Do you follow-up on any referral for tests, check-ups or labs?</td>
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<td>7. Do you arrange for your ride to medical appointments?</td>
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<td>8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?</td>
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<tr>
<td>9. Do you apply for health insurance if you lose your current coverage?</td>
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<tr>
<td>10. Do you know what your health insurance covers?</td>
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<tr>
<td>11. Do you manage your money &amp; budget household expenses (For example: use checking/debit card)?</td>
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</table>
Get Paid For Transition Support

- **Code 99240** can be billed when a **scorable** transition-readiness assessment is completed by the patient
- Coding and Reimbursement Tip Sheet [http://www.gottransition.org/resourceGet.cfm?id=353](http://www.gottransition.org/resourceGet.cfm?id=353)

**Coding and Reimbursement Tip Sheet for Transition from Pediatric to Adult Health Care**

*Margaret McManus, MHS*
*The National Alliance to Advance Adolescent Health*

*Richard Molteni, MD*
*American Academy of Pediatrics*
Arthritis Foundation Transition Toolkit

www.jatransition.org launched in 2013

• **For youth and families** to support successful transition
  • Resource library
  • Transition readiness assessment and ability to track scores
  • Skill-based worksheets with homework assignments
  • Separate login/format for youth and caregivers

• **New Provider Portal** for adult & pediatric rheumatology providers
  • 6 Core Elements
  • ACP/ACR tools
Welcome to the Arthritis Foundation Transition Toolkit

This website is designed to prepare youth with rheumatic diseases and their families for the transition to healthy adulthood.

Resource Library
Browse for health information and learn useful healthcare skills

Transition Toolkit
Test your healthcare skills and build your own Transition Toolkit

Provider Portal
Improve transition processes in your rheumatology practice

WATCH OUR VIDEO

LEARN MORE
BUILD YOUR TOOLKIT
START IMPROVING
Provider Resource Library

• Contacted young adult before the first visit to welcome and answer questions

• Clarified adult approach to care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication

• Included self-care goals and prioritized actions in plan of care
Canadian – Good to Go Transition Program

Good 2 Go Transition Program -- MyHealth Passport

Welcome to MyHealth Passport, a project of the SickKids Good 2 Go Transition Program. MyHealth Passport is a customized, wallet-size card that gives you instant access to your medical information. It can be used when you go to a new doctor, visit an emergency room or are writing your first novel and want the names of your medications for your hero.

Start by filling out the information below.

CREATE PASSPORT

Passport

Lupus
Maladie inflammatoire intestinale
Marrow Failure
MEDICATION RECORD
Mental Health
Metabolic
Morphia
Multiple organ transplant
Multiple Sclerosis
Muscular Dystrophy
Myasthenia Gravis
Neurofibromatosis
Obesity
Orthopaedics
Paeediatric Stroke
passport genifique
PKU
Primary Ciliary Dyskinesia or Bronchectasis
Prescribed Hypertension
Rheum
Rheumatologie
Rheumatology
Science on us... under construction
Sickle Cell
Spina Bifida
Thalassemia
Urology
Vascular Anomalies
Ventilation Non Invasive
Ventilation with trach
UW MEDICINE
TRANSITION CARE PROGRAM (TCP):
BRIEF SUMMARY
The TCP is an intake team that transitions patients into UW Medicine and coordinates care with the appropriate teams & resources.
What is “successful” transition?

• Patient measures:
  • Medication adherence
  • Disease control
  • Patient/family satisfaction
  • Disease Control
  • Long-term damage

• Systems measures:
  • Transfer to adult provider without gaps in care
  • Decreased health care costs
Evidence for Health Care Transition Support

Without transition support

• Poorer health
• Worse quality of care
• Increased health care costs
Transition: The Take-Home

• Many patients have ongoing disease into adulthood
• Not all patients are prepared for the transition to adulthood and adult rheumatology care
• Affected by health-system, patient and physician factors
• Preparation may improve patient and systems outcomes
• Transition to adult care for youth with rheumatic diseases was a health policy priority
• Resources are available to help you successfully transition your patients
Transition: Resources

• ACR/ACP downloadable tools to improve transition of youth with JIA and SLE: [https://www.rheumatology.org/Practice-Quality/Pediatric-to-Adult-Rheumatology-Care-Transition](https://www.rheumatology.org/Practice-Quality/Pediatric-to-Adult-Rheumatology-Care-Transition)

• Arthritis Foundation Transition Toolkit web-based tool to support families and providers: [http://www.jatransition.org](http://www.jatransition.org)

• Billable CPT code for transition readiness assessment [http://www.gottransition.org/resourceGet.cfm?id=353](http://www.gottransition.org/resourceGet.cfm?id=353)
Seattle Children’s Rheum Transition Project

The SCH team:
- Matt Basiaga, MD
- Albert Chow, MD
- Kate Coffee, RN

SCH Consultants:
- Endocrinology (Craig Taplin, MD)
- Adolescent Medicine (Laura Richards, MD)

Adult Provider Partners:
- Jenna Thomasen, MD (UW)
- Amish David, MD (VM)

We welcome your input/participation
Seattle Children’s Rheum Transition Project

• Start discussion at 12 years old (AAP recommendation)
• Age-dependent checklist administered every year
• Annual “transition day” for patients to come, learn about how to overcome common problems
• Communication with adult providers via letter, phone call
• Outcome: Follow up with patients – 3 months, 6 months, 12 months
Seattle Children’s Rheum Transition Project

• Start discussion at 12 years old

• Age-dependent checklist administered every year
  • Do not transition until milestones are met
  • Transition counselor
  • Identify complex patients to send to UW transition program
Seattle Children’s Rheum Transition Project

• Start discussion at 12 years old
• Age-dependent checklist administered every year
• Annual “transition day” for patients to come, learn about how to overcome common problems
  • Social work –
  • Financial aid counselor – insurance
  • Pharmacist
  • Adult rheumatologist – welcome, what to expect
Seattle Children’s Rheum Transition Project

• Start discussion at 12 years old
• Age-dependent checklist administered every year
• Annual “transition day”

• Communication with adult providers
  • Letter adequate? Or phone call as well?
  • Rheumatology vs. PCP
  • Visit to adult clinic prior to 1st appointment?
  • Or longer visit with tour, meet the staff opportunity?
  • Alternate peds/adult appointments for first 2?
Seattle Children’s Rheum Transition Project

• Start discussion at 12 years old
• Age-dependent checklist administered every year
• Annual “transition day” for patients to come, learn about how to overcome common problems
• Communication with adult providers via letter, phone call

• Outcome: Follow up with patients – 3, 6, 12, 24 months
  • Did they attend an appointment with an adult rheumatologist?
  • Are they filling Rx?
  • ED visit rate?
  • Focus on SLE, JIA, JDM, scleroderma, vasculitis
Questions

• How do NW rheumatologists see transition?
• What do we need to do differently for patients in Seattle vs. distant cities in WA, AK?

• How do we involve the pediatricians? Internists?
• Patients/families?
Seattle Children’s Rheum Transition Project Timeline

• May 2017: Finalize plan with pediatric rheumatologists
  • *Presentation to Cure Juvenile Myositis patients/families*

• June 2017: Circulate draft plan to WA, AK adult rheumatologists, families, conduct survey for input
  • Phil - Can we send an email through NW Rheum? Or how?

• August 2017: Finalize plan, designate roles, locations

• September 2017: Initiate new program

• Outcomes: survey patients – 3, 6, 12, 24 months
Get Out of My Life,
but First Could You Drive Me and Cheryl to the Mall?

Revised and Updated

A Parent's Guide to the New Teenager

Anthony E. Wolf, Ph.D.
Thank you
Dr. Erica Lawson

Assistant Professor of Pediatrics, Rheumatology
University of California, San Francisco, School of Medicine