



GENECIS: Challenging Injustice, Valuing Diversity in a Pediatric Transgender Program

2017 Equity and Diversity Conference
Denton, Texas
February 23, 2017

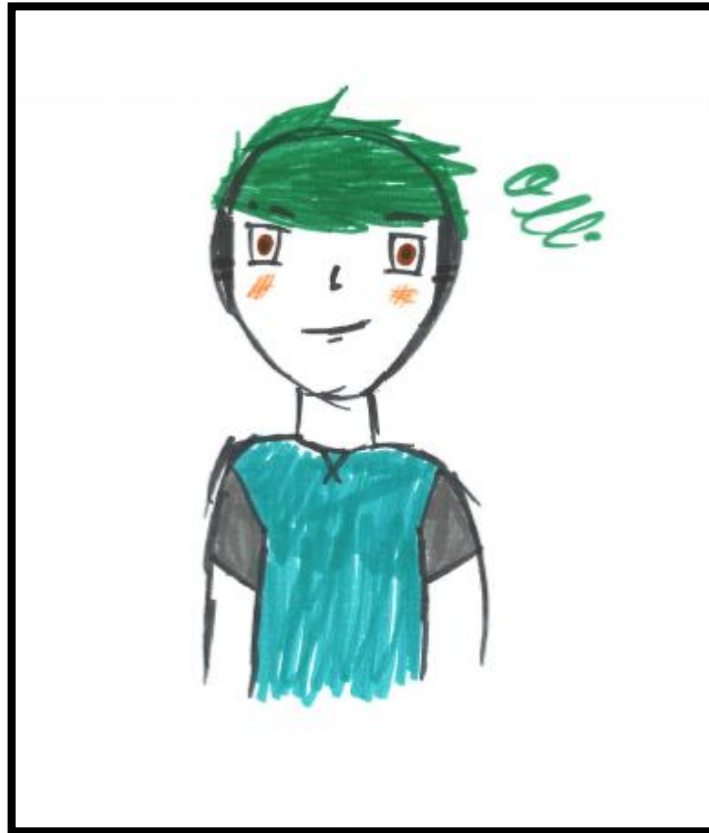


Presenters

- Meredith R. Chapman, MD
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 - Medical Director Consult and Liaison Services, Children's Medical Center
- Laura E. Kuper, Ph.D.
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Disclosures

- Dr. Meredith R. Chapman
 - I have no financial or other personal conflicts of interest to disclose



Learning Objectives

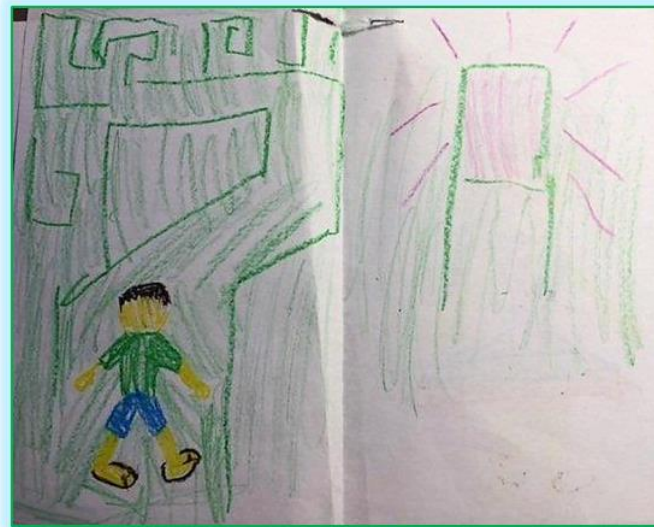
- Discuss challenges faced when starting and growing a complex multidisciplinary care program in a novel field, with limited resources and in a conservative community
- Identify important considerations in the development of clinical services for transgender youth
- Explain ways in which to improve communication and collaboration with patients, families, health care providers and the public to address inequalities and promote diversity.

GENder Education and Care Interdisciplinary Support (GENECIS) Mission Statement

- **Make life better for children and adolescents with gender dysphoria by providing for:**
 - The psychological health and social-emotional needs of transgender youth and their families
 - Access to gender affirming medical care, including puberty suppression and hormone replacement therapy
 - Education to the medical community and public on issues relating to gender non-conformity
 - Research to better understand and improve the medical care of transgender youth

GENECIS Multidisciplinary Objectives

- Resolve real world or complex problems
- Develop consensus clinical definitions and guidelines
- Provide comprehensive health services
- Create comprehensive research questions



Resolve Real World or Complex Problems

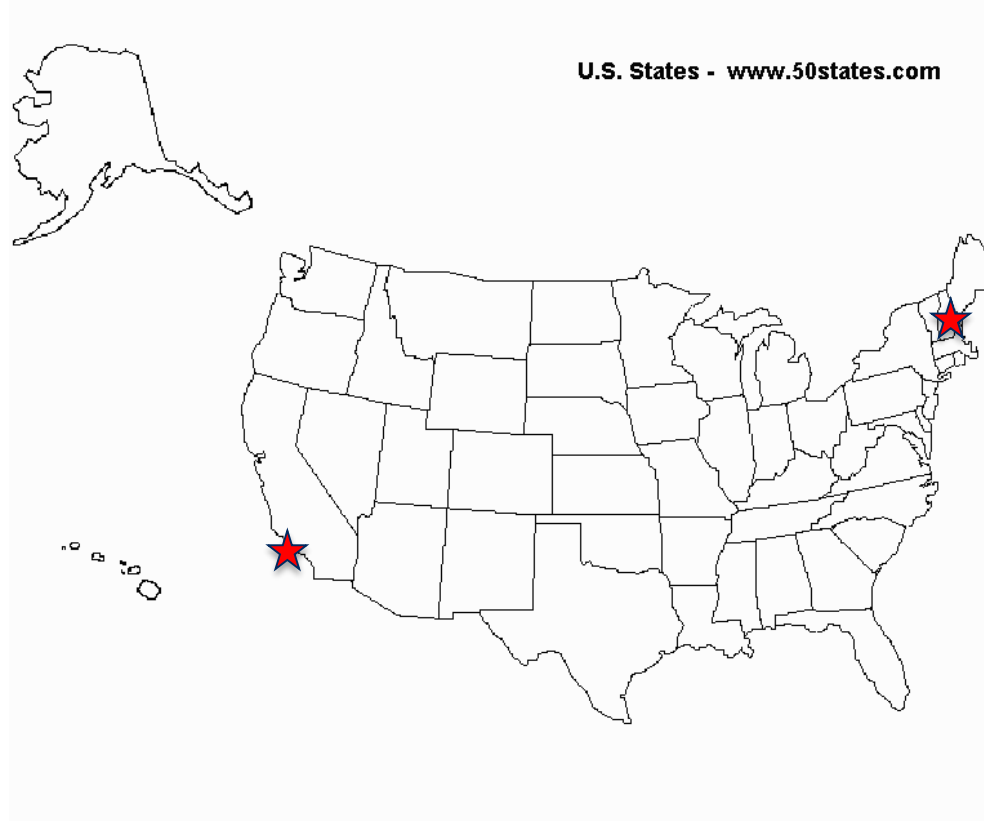


Establishing the Clinic: Evan's Story

Youth Necessitated, Parent Facilitated



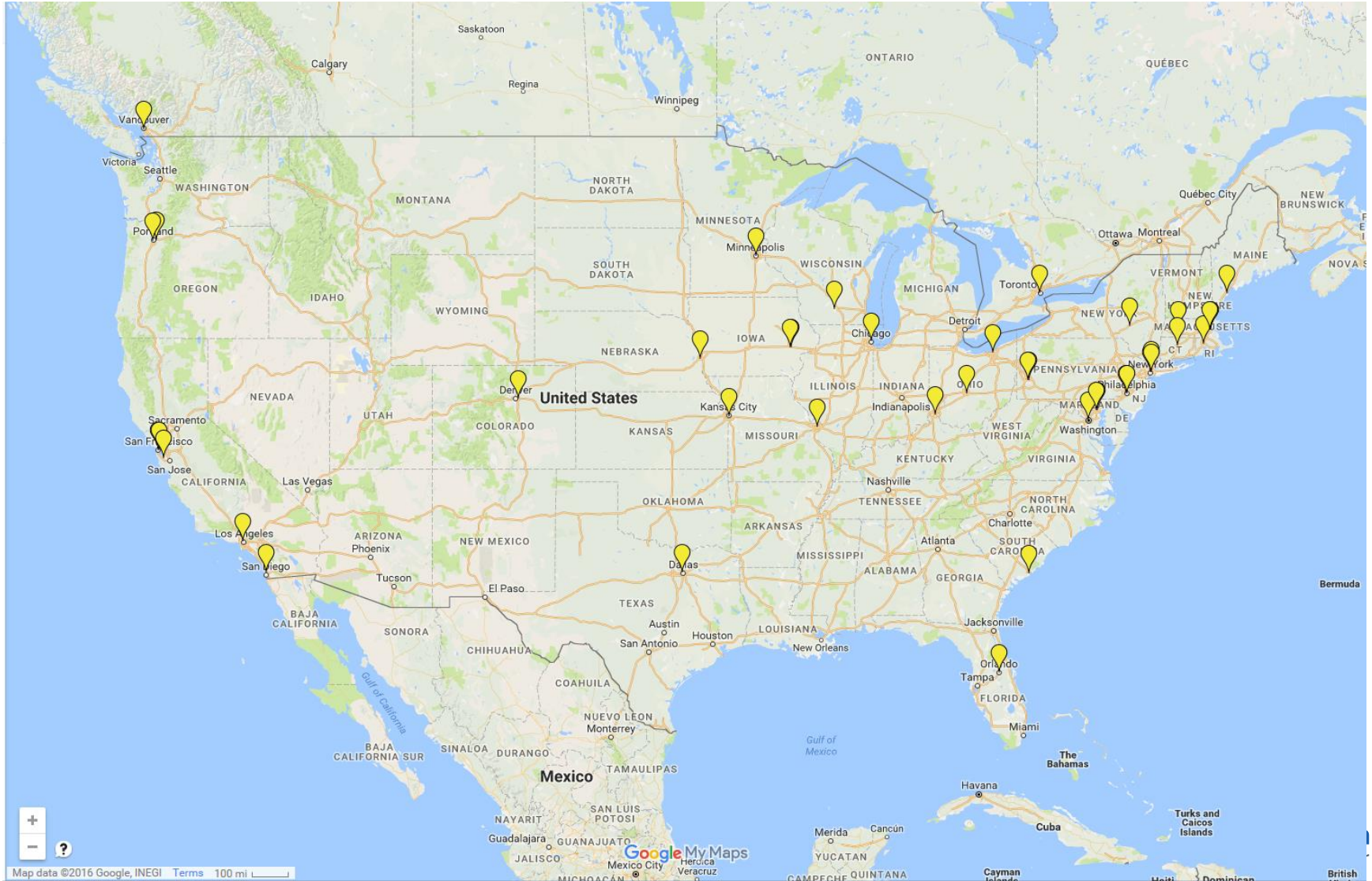
US Gender Programs for Children and Adolescents circa 2012



Center for
Transyouth
Health and
Development
at Children's
Hospital Los
Angeles

Gender
Management
Service
(GeMS) at
Boston
Children's
Hospital

US Gender Programs for Children and Adolescents in 2017





Boston, 2013

children'shealth[®]
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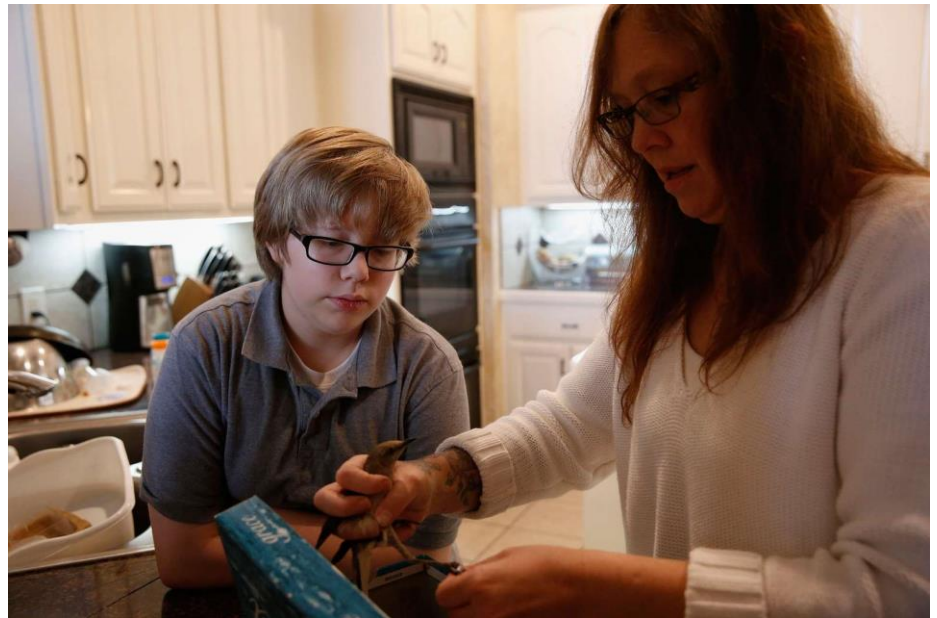
UTSouthwestern
Medical Center

Formally Educating Myself

- Read books:
 - Gender Born, Gender Made
 - The Transgender Child
- Consulted textbooks:
 - Chapter 24, Gender Identity Disorders Peggy T. Choen-Kettenis in *A Clinician's Handbook of Child and Adolescent Psychiatry*
- Reviewed the literature:
 - WPATH Standards of Care Version 7
 - Endocrine Treatment of Transsexual Persons: An Endocrine Society Clinical Practice Guideline
 - HRC's Growing Up LGBT in America and Supporting and Caring For Our Gender Expansive Youth
 - American Journal of Psychiatry
 - Pediatrics
 - Journal of the American Academy of Child and Adolescent Psychiatry

Informally Educating Myself

- Listened and learned from Trans youth and their families



Training Team Members

1. Visit to GeMS Boston Children's Hospital
 - Peds endo, psychologist, psychiatrist, social worker
2. Training course at GeMS Boston Children's program
 - Peds endo, psychiatrist, social worker
3. Hosted founding Psychologist from the GeMS program:
 - Training on mental health assessments
 - Psychologists, psychiatrists, social workers, LPC
4. National conferences:
 - Philadelphia Trans Health Conference (social workers)
 - WPATH Certified Foundations Training Course Transgender Health: Best Practices in Medical and Mental Health Care (psychiatrist)

Identification of Community Resources and Referrals

- Identification through youth and family input
 - Contacted and met with community providers
 - Obtained information on treatment approach/experience in working with Trans youth
 - Built a referral list
 - Provided free training with psychologist from GeMS
- Adult and youth advocacy groups
 - Met with representatives for guidance
 - Resources for community support (school, legal)

Institutional Support



Perrin White, MD
Director of the Pediatric Endocrinology
Expert in CAH/DSD

Recommendations:

1. Write a protocol
2. Convince the Chief of Pediatrics
3. No cross-sex hormones
4. All patients have to be in a research database

Institutional Support-Obtained

- With multidisciplinary input wrote a protocol based off the GeMS clinic at Boston Children's Hospital
- Obtained approval from the Chief of the Pediatrics
 - Suicide risk
 - Standard of Care (Endocrine Society/WPATH guidelines)
 - Opportunity to be the 1st program in the Southern US
 - US News and World Report Children's Hospitals Rankings and Ratings

Business Plan

- All patients would NOT have to be in a research database, but would be invited to participate: thanks to IRB
- Yes to cross-sex hormones: thanks to our psychiatrist
- Business plan required
 - Goal: no significant monetary loss
 - Calculate patient volume and resources for each patient based on the clinical protocol
 - Financial estimation: input from Program Development Department

Initial Business Plan

- Patient volume growth over 5 years:
 - 6 referrals/month for 3 years, then 4/month
- Resources: 0.5 social worker, 0.5 research coordinator
 - Participate without dedicated protected time:
 - 3 psychologists, 1 psychiatrist, 1 LPC, 1 pediatric endocrinologist, 1 adolescent medicine physician, 1 nurse (<20% of their time)
- Positive revenue after 2-3 years
- Final approval of program in the fall of 2014 but “we won’t market the clinic...”

Lessons Learned

UNDERESTIMATION

- Patient growth:
 - 20 referrals/month (vs. 6) > 1 year
- Psychiatry needs (high comorbidity)
- Social work time
- Administrative time for the Medical Director
- Complexity of coordination between disciplines/services
- Medical Director difficulties arising from not being a mental health provider
- Time spent in insurance coverage of Lupron/Histrelin
- Time spent in communication with the media
- Requests to provide education to other providers/schools

Business Plan- Revised

REVISED BUSINESS PLAN 6 months after opening:

1. Full time Social Worker
2. Half time Clinical Psychologist

REVISED BUSINESS PLAN 12 months after opening:

1. Psychiatry patient care time (15% but not enough)
2. Full time Program Coordinator
3. Full time Nurse
4. Full time Licensed Professional Counselor
5. Administrative time for the Medical Director (10% but not enough)
6. Mental Health Director with 10% administrative time
7. Full time Clinical Psychologist

Media Exposure

“We won’t market the clinic……”

1. [KTVT-TV \(CBS\)](#): Dr. Ximena Lopez interviewed about the mental health struggles of transgender children (*May 13, 2016*)
2. [DFW Child](#): Raising a Transgender Child (*March 2016*)
3. [Dallas Voice](#): Time to Thrive comes to DFW (*Feb. 5, 2016*)
4. [Dallas Voice](#): A new trans generation – Print attached (*Jan. 30, 2016*)
5. [Cosmopolitan.com](#): How I Started the Only Clinic for Transgender Kids and Teens in Texas (*Jan. 20, 2016*)
6. [Scientific American Mind](#): Debate is growing about how to meet the urgent needs of transgender kids (*Jan. 2016*)
7. [Al Jazeera America](#): Transition at 12: Growing up transgender in Texas (*Sept. 20, 2015*)
8. [KERA](#): Helping Transgender Youth Transition (*June 22, 2015*)
9. [KERA](#): Inside A Dallas Clinic For Transgender Kids (*June 22, 2015*)
10. [The Washington Times](#): Children’s hospital opens clinic for transgender children (*June 14, 2015*)
11. [The Dallas Morning News](#): Free to be themselves (*June 7, 2015*)
12. [WUSA-TV \(CBS\)](#): Kammie’s story: Being a transgender teen (*April 23, 2015*)
13. [The Huffington Post](#): ‘Finally Normal’: How A New Medical Landscape Is Changing Life For Trans Youth (*March 18, 2015*)
14. [WFAA-TV \(ABC\)](#): Program for transgender children unique in the Southwest (*March 12, 2015*)
15. [AAP News](#): Gender dysphoria associated with mental health concerns (*Feb. 23, 2015*)
16. [KDFW-TV \(FOX\)](#): GENECIS Program – clip attached (*Feb. 21, 2015*)
17. [KUVN-TV \(Univision\)](#): Menores con trastorno de identidad (*Feb. 13, 2015*)
18. [KDAF-TV \(CW\)](#): New Program Helps Transgender Teens Find Their Identity (*Feb. 12, 2015*)
19. [KTVT-TV \(CBS\)](#): New Transgender Hospital Program Introduced To Dallas (*Feb. 12, 2015*)
20. [KERA](#): What's Gender Dysphoria? This 15-Year-Old Will Tell You (*Jan. 27, 2015*)

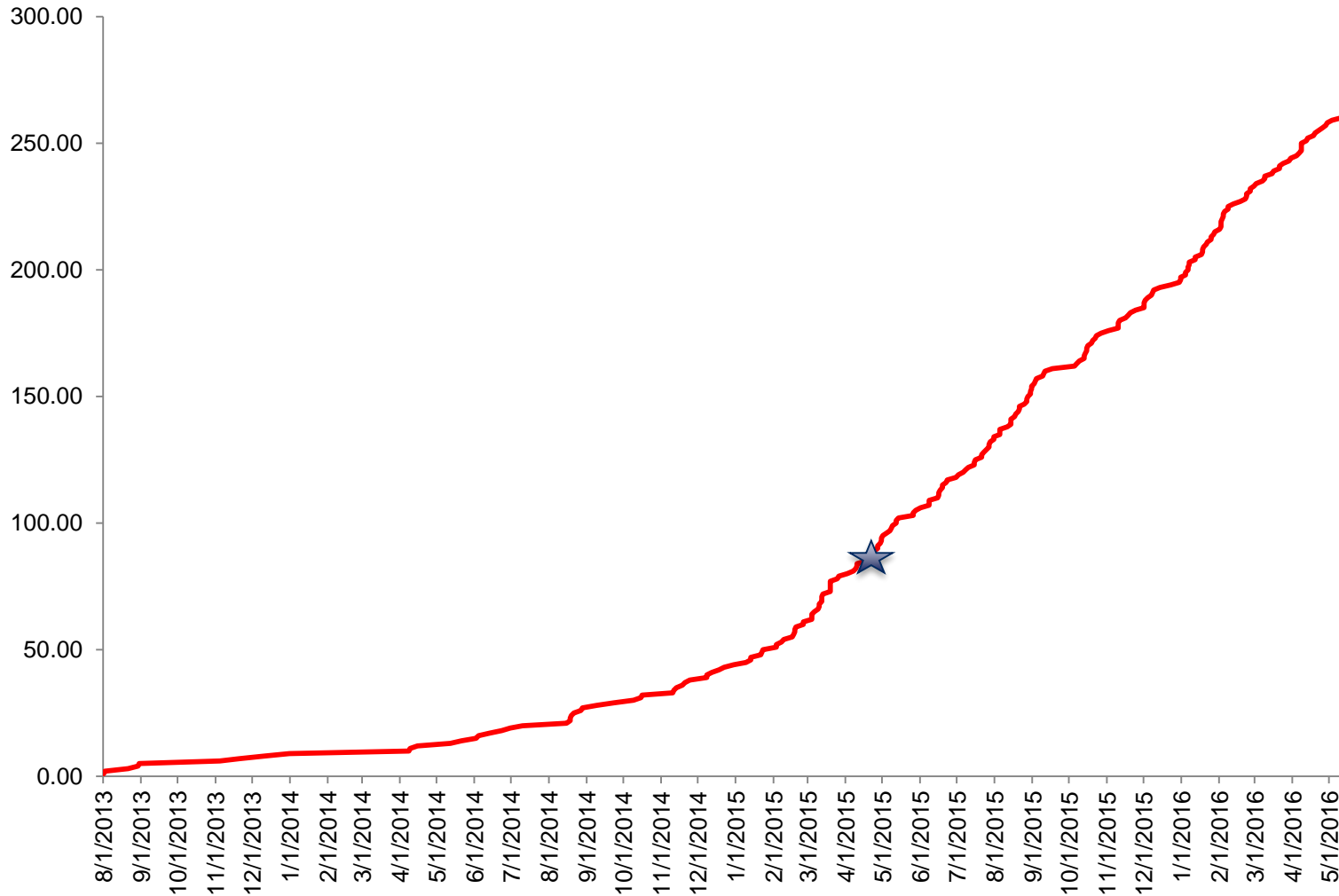


Media Exposure

Reactions in the community:

- Very positive overall, leading to requests for education
- Christian ministers called hospital to inquire more- developed a Q&A document used by PR
- Contacted by conservative/religious radio/media (denied interviews)
- Negative comments:
 - Radio host from a very conservative Christian radio station
 - Individual comments/posts on online articles

Volumes and Demographics Over Time





Develop Consensus Clinical Definitions and Guidelines

Creating a Clinical Protocol

- Accessing the clinic
- Phone intake
- Letter of support
- Initial comprehensive assessment
- Multidisciplinary staffing
 - Match youth and families with providers
- Initial physical health visit
- Follow-up physical health visits
- Annual reassessment
- Transition of care

Genecis Program

Share:     



I would like to...



Find a Doctor ›



Locations & Directions ›



Login to MyChart ›



Refer a Patient ›



Request an Appointment ›



Visitor & Patient Guide ›

Contact

**Children's Health Specialty
Center Dallas**

214-456-0262

Creating a Clinical Protocol Letter of Support

Client Profile:

- ✓ Client Age, Education Level, and Brief Family History
- ✓ How Client was Referred to You
- ✓ Parental Support (if any)

Relevant History:

- ✓ Look Into Client's Life and Gender
- ✓ Gender Roles in Family
- ✓ Significant Events/Concerns within Relevant Gender History
- ✓ Brief Explanation of Transition (if any)

Support System:

- ✓ Family System Support
- ✓ School/Friend Group Support
- ✓ Other Areas of Support (Religious, Community, Extended Family)
- ✓ Counseling Support & Willingness to Continue Counseling

Readiness Criteria:

- ✓ Relevant Mental Health History (i.e. depression, self-harm, anxiety, suicidal ideations, etc.)
- ✓ Include Past and Present Mental Health History
- ✓ Gender Dysphoria Criteria Present with Client
- ✓ Abuse/Trauma Assessed

Therapist Experience:

- ✓ Your Experience/Background Working with TGNC Youth
- ✓ Any Relevant History

Creating a Clinical Protocol

Initial Comprehensive Assessment- Measures

Measures

- Completed at home:
 - Child Behavior Checklist & Youth Self Report
 - SCARED (anxiety), QIDS (depression)
 - Social Communication Questionnaire (autism spectrum)
 - Quality of Life (including family impact)
 - Gender Identity Questionnaire (11 and under)
- Completed in person:
 - Interpersonal Needs Questionnaire
 - Acquired Capability for Suicide
 - Body Image Scale
 - Columbia Suicide Severity Rating Scale & Risk Assessment
 - Self-portrait
 - Children: Sentence completion, family drawing

Creating a Clinical Protocol

Initial Comprehensive Assessment- Interview

Clinical interview

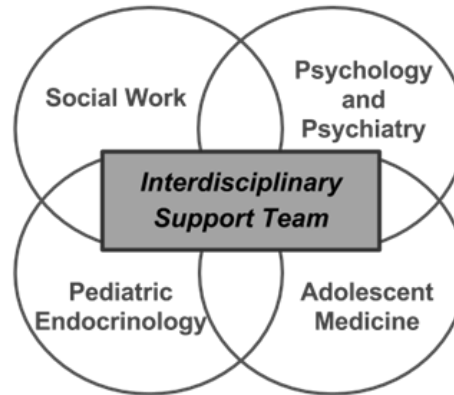
- Gender identity/expression
 - Transition steps, disclosure, reactions to puberty, desired medical interventions
 - Support/resources
- Psychosocial functioning
 - School, family, friends
- Mental health history
- Parent and Youth portions

Creating a Clinical Protocol

Multidisciplinary Staffing

- Frequency
- Participants
- Agenda
- Challenges
 - Explaining provider roles:
 - Families, other providers, within the team
 - Role of initial comprehensive assessment
 - Providing information vs. recommendations
 - Discussion of most appropriate next steps:
 - Who makes “decision” regarding treatment approach
 - Role of advocacy

Creating a Clinical Protocol Moving Towards Transdisciplinarity



Identified needs for more holistic care for youth and their families

- Spiritual needs: Pastoral Care
- Educational needs: School Services
- Pet therapy
- Difficulty coping with examination/procedures: Child Life Department ?
- Voice: Speech Therapy?



Barriers to Clinical Care

Insurance: Physical Health

- **Lupron/Histrelin:**
 - Letter of Medical Necessity: Standards of Care
 - When not covered, high deductible:
 - Histrelin implant
 - \$2000 cash pay discount hospital program
 - \$2500 discounted price if ordered by gynecology
 - Leave Histrelin for 2 years instead of 1
 - High dose progesterone (Provera)
 - Menstrual suppression only (Aygestin)
 - Spironolactone (Transgirls)

Barriers to Clinical Care

Insurance: Mental Health

- Hospital contracts vary between physical and mental health
 - Public insurance contracts for physical health but not most mental health services
- Gender dysphoria as a non-covered diagnosis for some commercial insurance plans
- Out of pocket expense if uninsured

Barriers to Clinical Care

Parental consent for medical intervention in patients younger than 18:

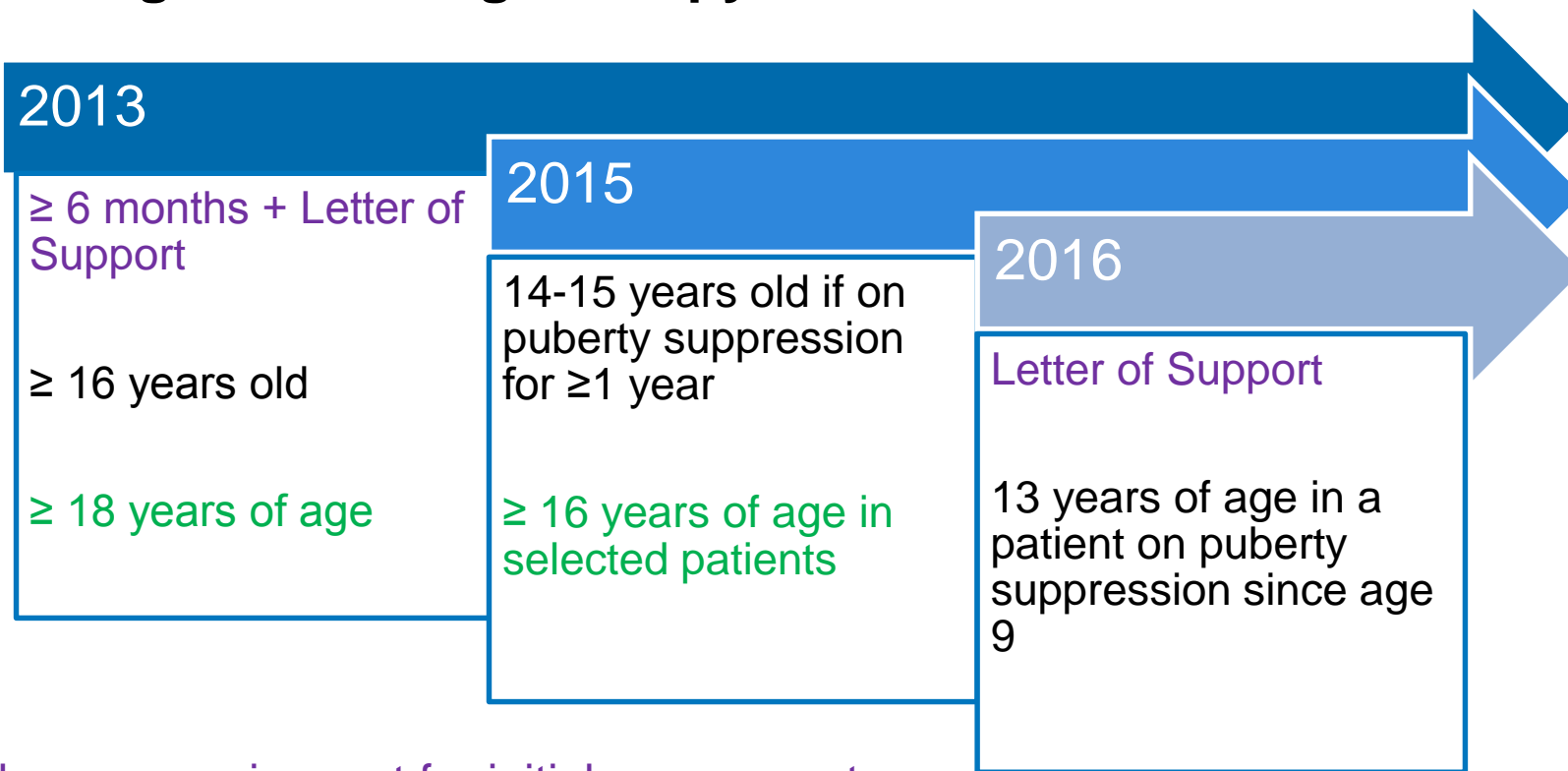
- Requirement for both parents/legal guardian's written consent
- When one parent/legal guardian is opposed:
 - Educate parent
 - Hospital Ethics committee
 - Reversible treatment (menstrual suppression; puberty suppression only in 17 year old)
- When one parent/legal guardian is “not in the picture”
 - Sign written consent form

Barriers to Clinical Care

Program Requirements Over Time

Deviations from standard of care/ practice guidelines

Timing of Affirming Therapy: Evolution over time



Therapy requirement for initial assessment
Cross sex hormone therapy
Mastectomy

Barriers to Clinical Care

Transition and Integration of Care

Lack of adult providers:

- Outreach to the affiliated University Endocrinology Department (adult)
- No program → Interest → Starting a program
- Developing a transition to adult care process
- Outreach to local plastic surgeons in the community and to affiliated University
 - Interest in the University but lack of available training
 - Referrals-mostly outside of the state

Lack of integration with HIV services

Health Literacy Documents

GENECIS: Our Program

GENder Education and Care Interdisciplinary Support

GENECIS: Becoming a Patient

GENder Education and Care Interdisciplinary Support

GENECIS: Prior to Your Visit

GENder Education and Care Interdisciplinary Support

GENECIS: Your First Visit

GENder Education and Care Interdisciplinary Support



**Provide
Comprehensive
Health Services**



Intra-institutional Care Coordination Programs and Departments

- Existing Psychiatry/Psychology programs
 - Inpatient
 - SPARC Intensive Outpatient (suicidality)
 - FORWARD Group (DBT Skills)
 - Outpatient
 - Identified providers with interest/experience to create a referral base
 - Emergency Department
 - Reworked safety assessment to include sexual orientation and gender identity

Intra-institutional Care Coordination Electronic Medical Record

Electronic Medical Record

- Gender marker and preferred name

The screenshot displays a patient header in an EMR system. The patient's name is "Zzztest, Genecis Nickna...". The header is organized into several columns of information:

Zzztest, Genecis Nic... Pref Name: Amber	MRN: 9614288 CSN: 82665150	DOB: 07/01/1998 Age Legal Gender: 17 yrs, M Gender Identity: Female Sex Assigned at Birth: Male	Rm/Bed: C4254-1 Allergies: Not on File Weight (kg): None BSA: Patient weight not recorded	Attending: Hicks, Barry A., MD Isolation: None Infection: None	Code: -	Class / Accommodation Inpatient, Med/Surg Guardian Pref Lang: English MyChart: Inactive
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Education and Training

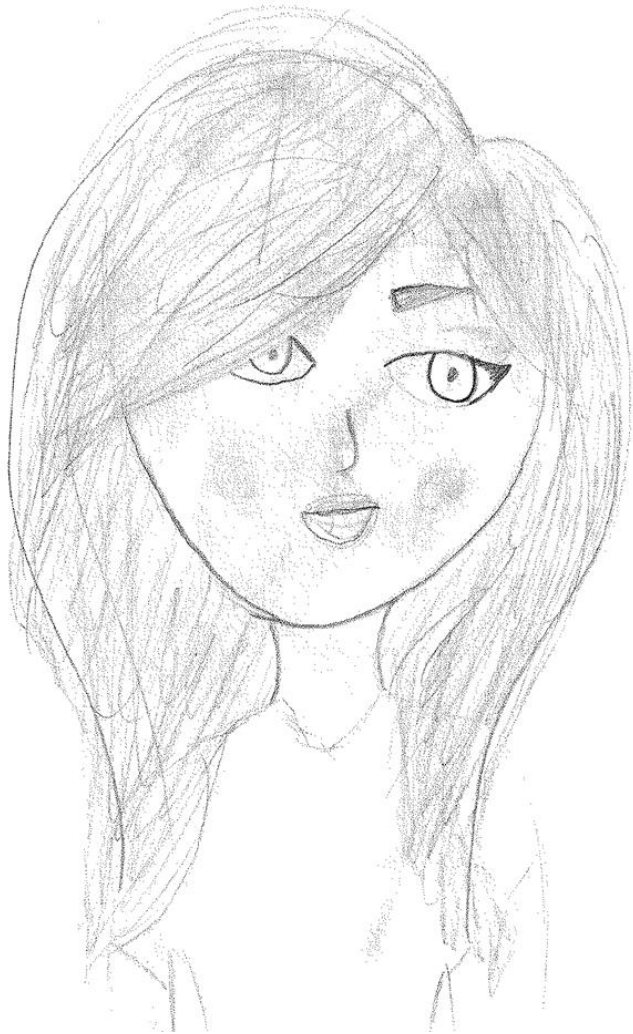
- Institutional
 - Didactics (general pediatricians, pediatric and psychiatric residents and fellows, medical students, psychologists)
 - Grand Rounds
 - Diversity Club
 - HEAL
- Local community
 - DISD MH professionals and school nurses
- Regional
 - DBP conference
 - APN conference
 - Region 10 school nurses
- National
 - HRC Time to Thrive
 - HRC Advisory Board
 - AACAP
 - Adolescent and Endocrine meetings

Barriers to Comprehensive Health Care

- High degree of psychosocial adversity
 - Few community supports
 - Lack of follow-up
 - Adherence to MH treatment plan
- Lack of MH providers
 - Lack of comfort working with transgender patients
 - Inadequate expertise in managing suicidality
 - Accessibility and insurance coverage issues
- High degree of communication/collaboration required

Opportunities for Growth

- School Services
- Child Life
- Individual and family therapy
- Psychiatric consultation and management
- Ongoing education/consultation both inside our institution and to the outside community
- Advisory Board
- Youth and parent support groups
- Voice therapy
- Institutional Diversity and Inclusion



Create Comprehensive Research Questions

Construction of a Clinically-Oriented Research Database

- Data points include:
 - Initial Comprehensive Assessment
 - Yearly Reassessment
 - Suicide Screening at every visit
- Challenges
 - Lack of well designed existing measures
 - E.g., Gender dysphoria
 - Difficulty capturing qualitative data
 - E.g., identity development
 - Complexities of tracking mental health and quality of life outcomes overtime
 - Research versus “standard of care”

Conclusions

- It takes many resources to start and sustain a clinic
- Large demand
- Unexpected support
 - Families, community, and institution
- Clinical consensus
 - Flexible and adapt to change
- Care coordination and mental health support are keys
- Unavoidable advocate and expert role



GENECIS Referral

214-456-0262

www.childrens.com/genecis

Question and Answer

