

# Lessons Learned in 10+ Years of Experience Using Puberty Blockers At VUMC Amsterdam

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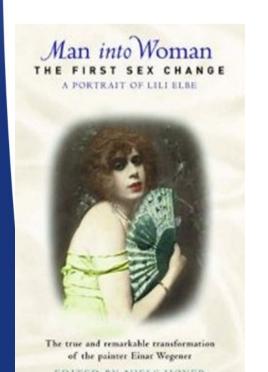
Agnodice, Lausanne, November 25 2016



# Transgender Care for Adults 1

Hirschfeld (1868 – 1935)

•Institut für Sexualwissenschaft



Lili Elbe(1886 – 1931)

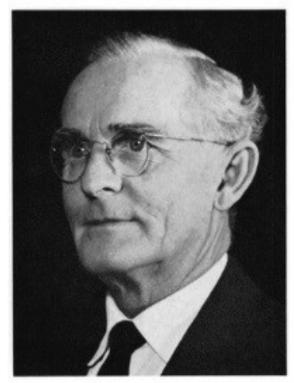




### Transgender Care for Adults 2

 First hormone treatment by Christian Hamburger (Denmark)

Christine Jorgensen
 "Classic treatment"



CHRISTIAN HAMBURGER





#### "Classical" Treatment

- Diagnostic phase
- Real life test /real life experience phase
- Cross-sex hormone treatment
- (Genital) surgery (SRS)
- Legal change

Not before 18 (21; 23) years

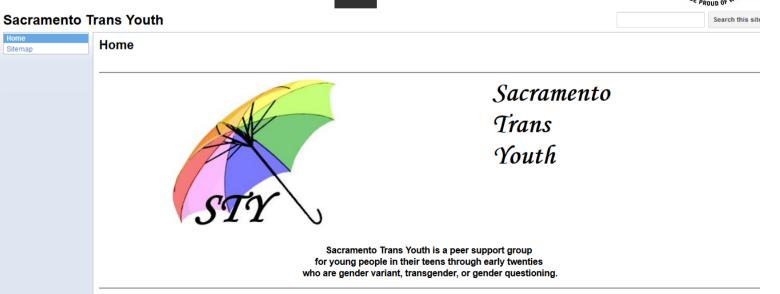




#### Situation Transgender Care Adolescents?

- Clinicians rejecting
- Mental health institutions no experience
- No place to go
- No subculture / Internet
- Waiting...







# Start Child & Adolescent Gender Identity Clinic (1987)

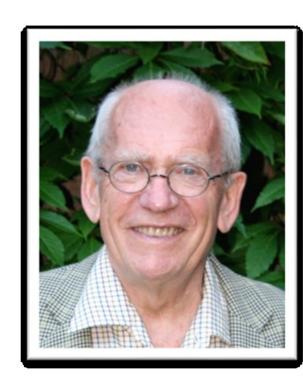
- Within department of child psychiatry only mental health care
- Referrals mostly >16 years
- Follow-ups in adults: postoperative functioning better in persons, treated at younger ages
- Yet, nothing to offer but psychotherapy



# Development of the "Dutch Protocol"

- Two stages
  - First stage 1987 2000
  - Seconds stage since 2000

 Collaboration with prof Louis Gooren at Vumc Amsterdam





# First Stage

- > 16 years
- Hormonal treatment staged
  - First anti-androgens, later estrogens for trans girls
  - First progesterone, later androgens for trans boys
- Very closely monitored



# Clinical Protocol According to Adult Standards of Care of WPATH

- Diagnostic phase (more extensive)
- Real life test /real life experience phase
- Staged cross-sex hormone treatment

- (Genital) surgery
- Legal change



# Strict Eligibility Criteria

- Long lasting gender dysphoria
- Stability or exacerbation of GD at start puberty
- No interfering comorbidities
- Support from family / social network
- A good understanding of the effects of treatment



# Follow-up Studies

- Cohen-Kettenis, van Goozen
   J Am Ac Child Adolesc Psychiat, 1997
- Cohen-Kettenis & van Goozen
   Eur Child Adol Psychiat, 1998
- Smith, van Goozen, Cohen-Kettenis
   J Am Ac Child Adolesc Psychiat, 2001
- Smith, van Goozen, Kuiper
   Psychol Med, 2005



#### Outcomes?

- Decrease of gender dysphoria
- Increase in body satisfaction
- Normal psychological / social functioning



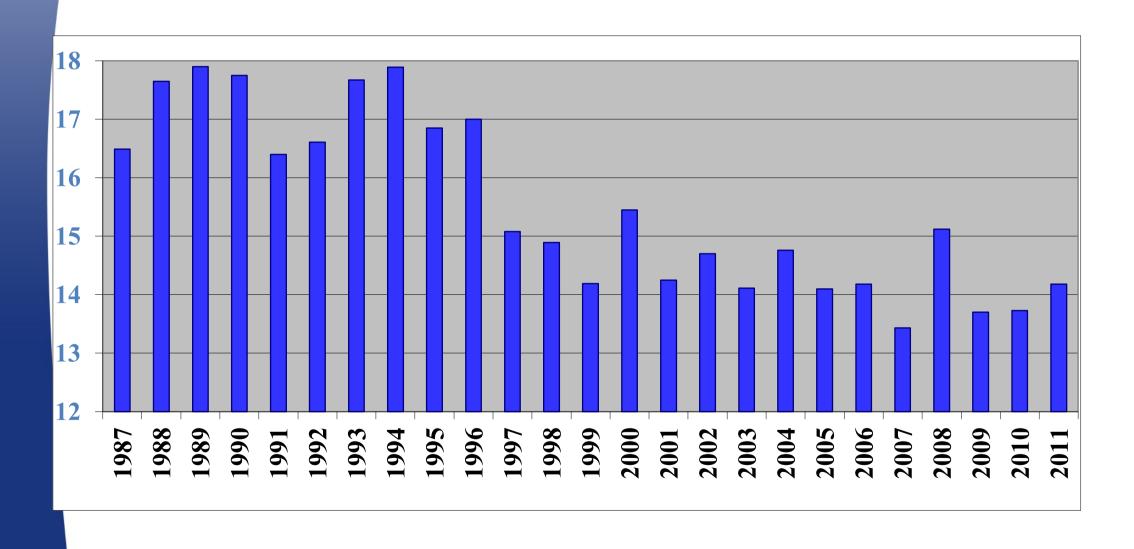
# Physical Appearance

- Treated in late Tanner stages (4 or 5)
  - Voice
  - Adam's apple
  - Beard growth
  - Facial bone structure  $\rightarrow$

Breasts



# Drop in Mean Age at Referral





#### **Second Step**

<11 years

1st Diagnostic phase

No Medical intervention

half a year

11/12 -15/16 years

'Prolonged diagnostic phase'

**Puberty Blocking** 

Completely reversible

max 4 year

15/16 to 18 years

Hormone treatment phase

Cross-Sex Hormones

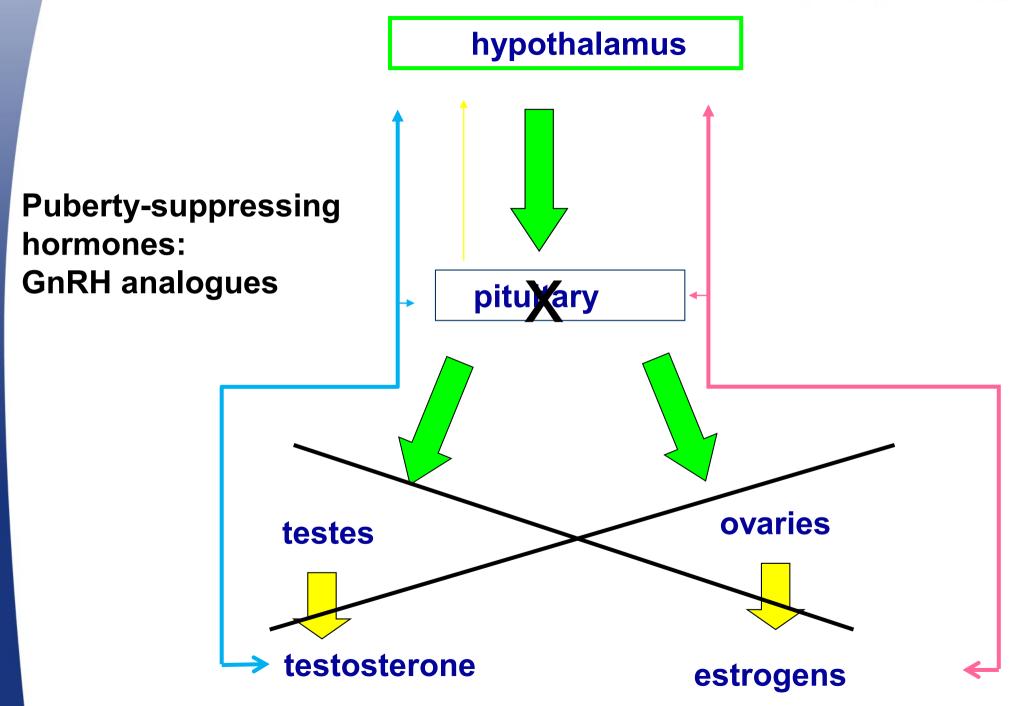
Partially reversible

Prof Henriette

Delemare

min 1 year







# **GnRH** analogues

- Much experience in children with precocious puberty
- Reversible



# Multidisciplinary C & A Team

- Child & adolescent psychologists
- Child & adolescent psychiatrists
- Psychometrist
- Pediatric endocrinologist
- Pediatric nurse

> 18 years endocrinologists, plastic surgeons, gynecologists



# Center of Expertise on Gender Dysphoria of the VU University Medical Center in Amsterdam





#### Child & Adolescent Services

- Latin America (Brazil)
- South-Africa
- Asia (Japan; Psychiatria et Neurologia Japonica, 2012)
- Australia
- New Zealand
- US 35 providers (Hsieh & Leininger, 2014)
- Canada
- Europe 

  Survey by Kaltiala-Heino (Finland)



#### Youth Specialized GI Services: European Survey

- 1. Belgium (1)
- 2. Finland (2)
- 3. Germany (3)
- 4. Italy (4)
- 5. Netherlands (2)
- 6. Northern Ireland (1)
- 7. Serbia (>16 years) (1)
- 8. Spain (3)
- 9. Sweden (2)
- 10.Switzerland (2)
- 11.UK (2)

12. Austria (1)

- Croatia (0)
- Denmark (planning)
- France (0)

Total = 24 services



#### First Criticism

#### At first:

#### Too progressive

- "Abuse of medical science"
- "Today's hype is tomorrow's scandal"
- Nazi's experimenting with children
- → Data base from the start of puberty blocking
- → Monitoring the adolescents clinically
- → Follow-up studies



#### Recent Criticism

#### Now:

- Too conservative
  - Age limits puberty blockers
  - Age limits cross-sex hormones
  - Age limits surgery (Milrod: How young is too young? JSM 2014)
- Too much involvement of mental health practitioners



### Wise decision?



#### Main Clinical Concerns

- Are GnRH analogues effective in transgender adolescents?
- Does a treatment starting with GnRH analogues at a young age result in good outcome?
  - Physically
  - Appearance
  - Mentally



# Is Treatment Starting With Puberty Blockers Effective?



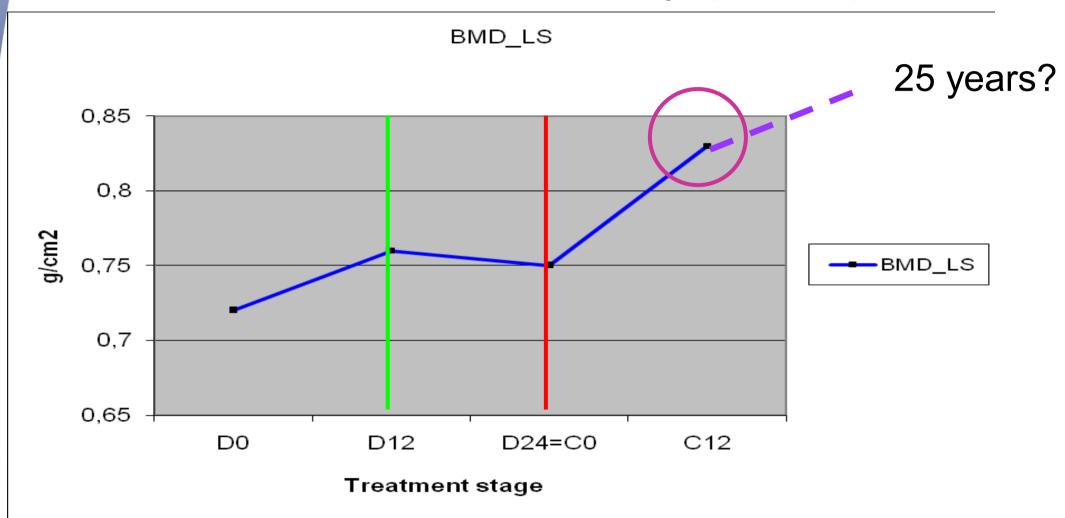
### Report Schagen et al, 2016

- Gonadotropins and sex steroids were suppressed within 3 months
- Testicular volume decreased in transgirls
- Breast size reduction in some trans boys (only when in Tanner 2/3)
- No abnormalities of liver enzymes and creatinine

 Frequent routine monitoring of gonadotropins and sex steroids of liver enzymes and creatinine not necessary



### Bone Mass Density (BMD)

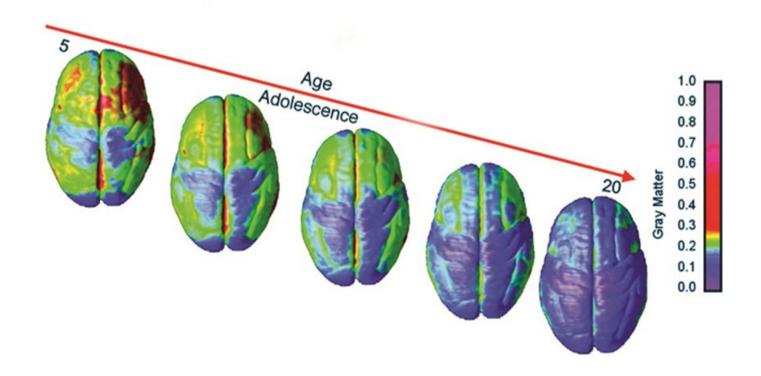


Delemarre van de Waal et al., 2004, 2006 Klink et al, 2015 Schagen et al, submitted



#### **Brain Effects?**

 No effects on executive function (Staphorsius et al, 2015)





# Summary Physical Effects

- GnRH analogues are effective
- Generally good outcome: no serious negative side effects
- Appearance in line with experienced gender



# Psychological support, puberty suppression and psychological functioning (N=201)

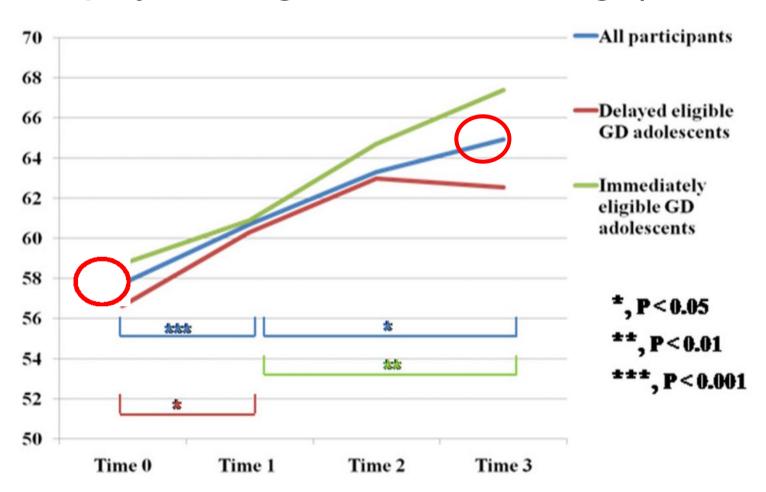


Figure 2 Gender dysphoria adolescents' psychosocial functioning (CGAS) at baseline, after psychological support, and after puberty suppression

(Costa et al, 2015)

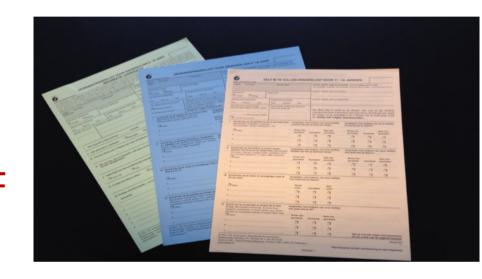


### **Emotional and Behavioral Functioning**

Measures (Achenbach):

**Teacher Report Form** 

TRF



**Child Behavior Checklist** 

**CBCL** 

Youth Self Report

**YSR** 

(Steensma et al., 2013, De Vries, et al., 2016)



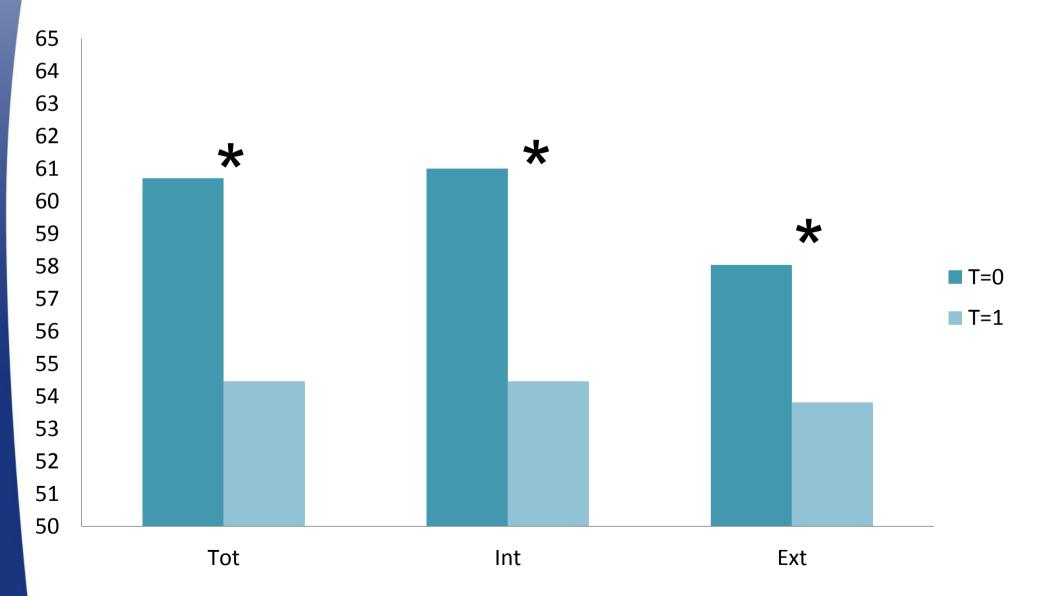
### **Emotional and Behavioral Functioning**

(Achenbach, 1991)

CBCL, TRF, YSR withdrawn Internalizing somatic complaints anxious/depressed social problems thought problems attention problems Externalizing delinquent behavior aggressive behavior

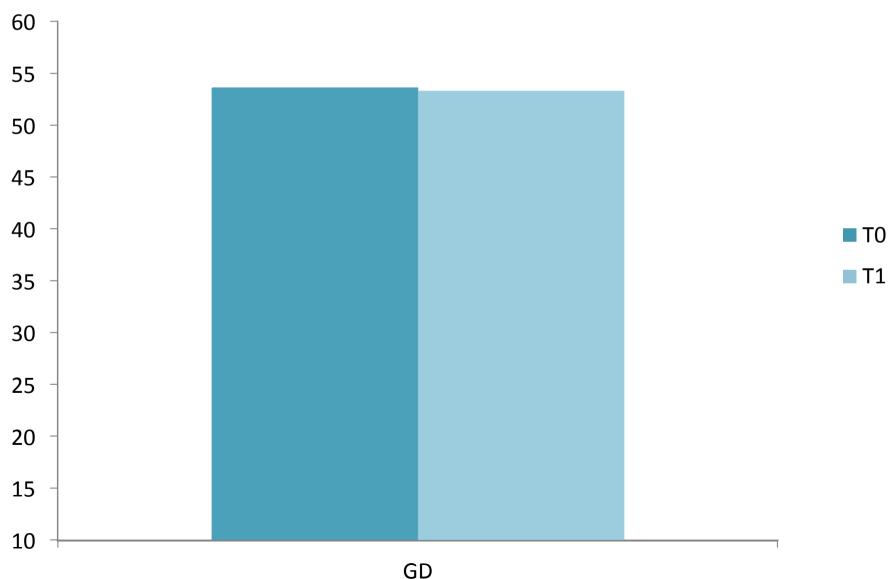


# Psychological Functioning Before and After Puberty Suppression (CBCL = parent report)





# But No Change in Gender Dysphoria



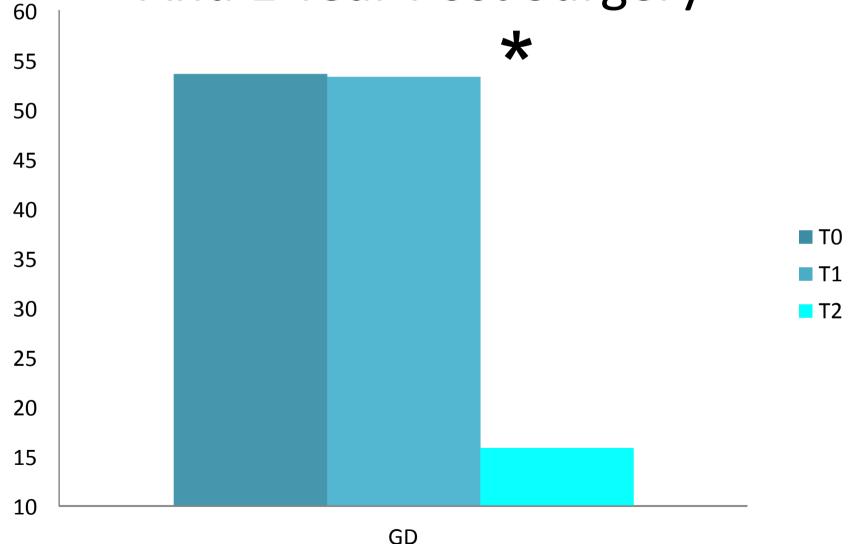


→ 2<sup>nd</sup> Follow-up after 'gender affirming treatment' (puberty suppression, cross-sex hormones and at least 1 year post surgery)

(de Vries et al, 2014)



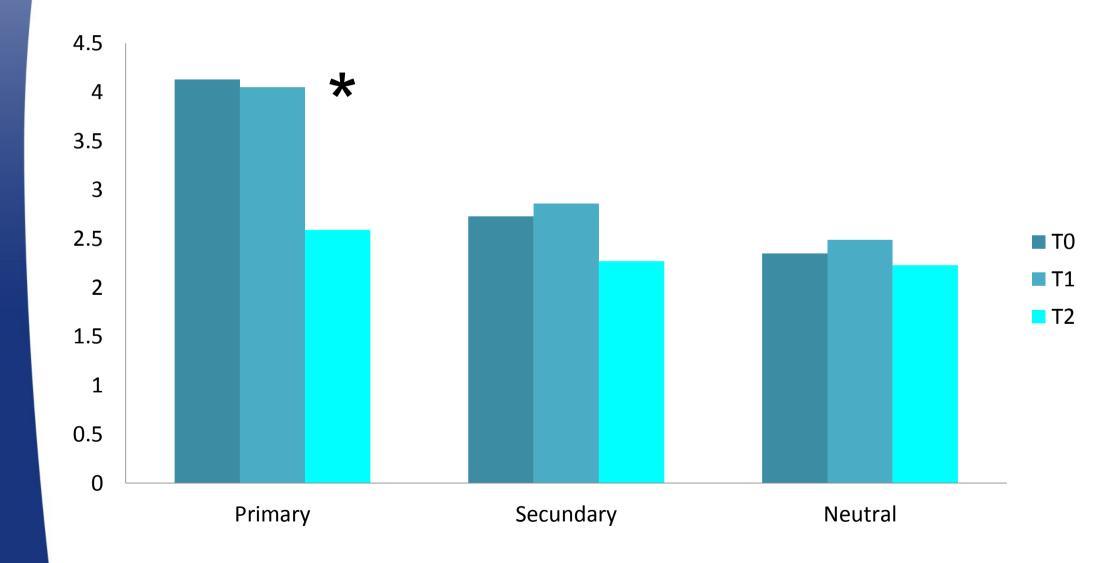
## GD Before And after Puberty Suppression And 1 Year Post Surgery



GD only drops after cross-sex hormones and surgery



## Body Dissatisfaction Before and After Puberty Suppression and 1 Year Post Surgery (T0, T1, T2)





### Post-operative follow-up

- No gender dysphoria
- Satisfaction with body improved
- Psychological functioning improved
- Subjective well-being comparable to general population of young adults

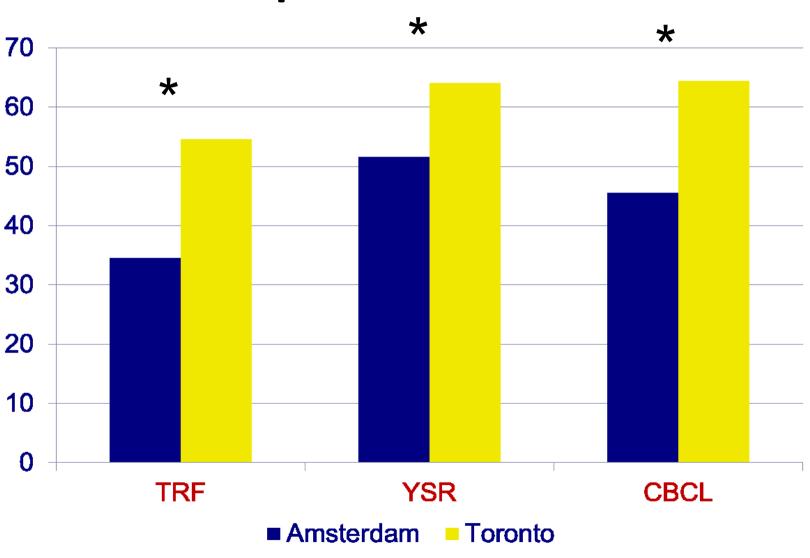
(de Vries et al, 2014)



# Do Transgender Adolescents Only Need Medical Treatment?

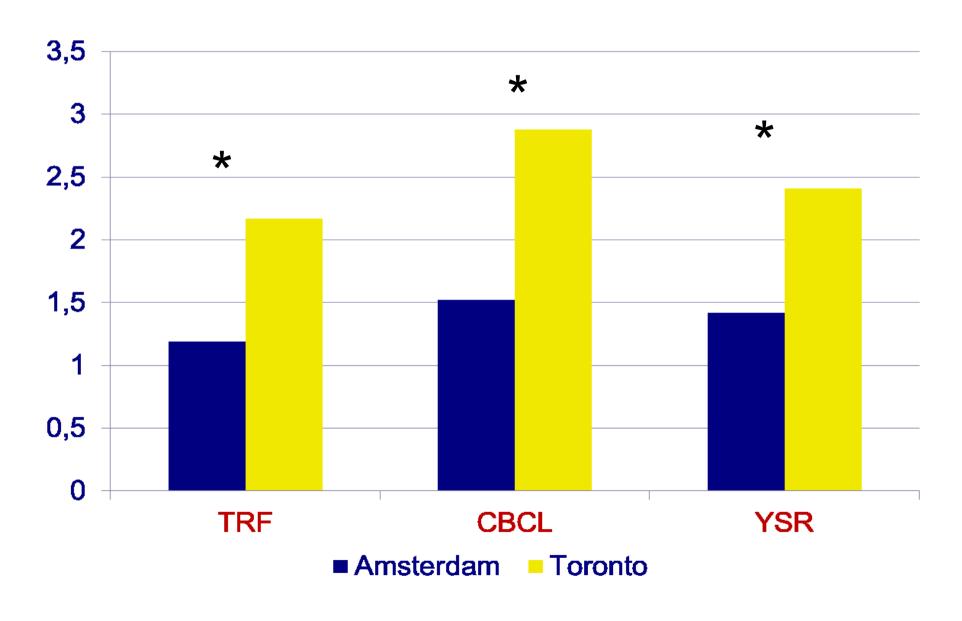


## Total problem score





### Peer Relations Scale





 Peer relations were the main predictor of total problem score

Peer relations should be addressed during counseling

(de Vries et al, 2016)



## Other Types of Care

#### **External factors**

- Hostile environment internalized transphobia;
   suicidality
- Binders for breasts resulting in broken ribs

#### Internal factors

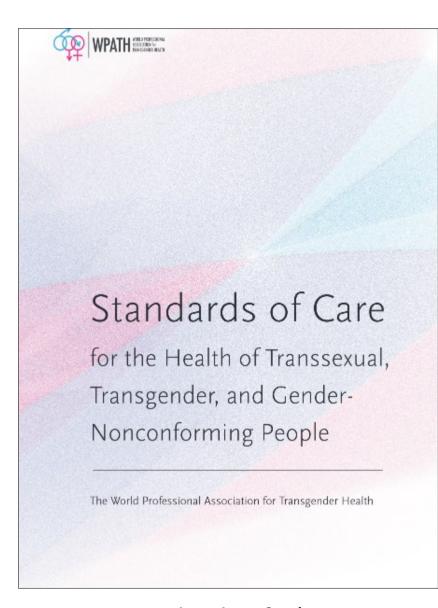
- Co-occurring psychological problems
  - Autism Spectrum Disorders (ASD) (guidelines by Strang et al, 2016)
  - -ADHD



#### International Guidelines 1

Standards of Care (7th),
World Professional Association
for Transgender Health
(WPATH)

- 15 languages
- 120 pages
- Educational



(Meyer et al, 2001; http://www.wpath.org/publications\_standards.cfm)



#### International Guidelines 2

- Clinical practice guidelines of the Endocrine Society (Hembree et al., JCEM, 2009)
  - Currently under revision

CLINICAL GUIDELINES

Endocrine Treatment of Transsexual Persons:

An Endocrine Society Clinical Practice Guideline







# Other Recommendations and Guidelines

- Report of American Psychiatric Association (2012)
- American Academy of Child and Adolescent Psychiatry (2012)
- Report of the American Psychological Association's (2009)
- Focus on Human Rights & Social Position



# Resolution of the World Medical Association, 2015

 The WMA urges that every effort be made to make individualized, multi-professional, interdisciplinary and affordable transgender healthcare available to all people who experience gender incongruence in order to reduce or to prevent pronounced gender dysphoria.



### Future Challenges

Fertility issues

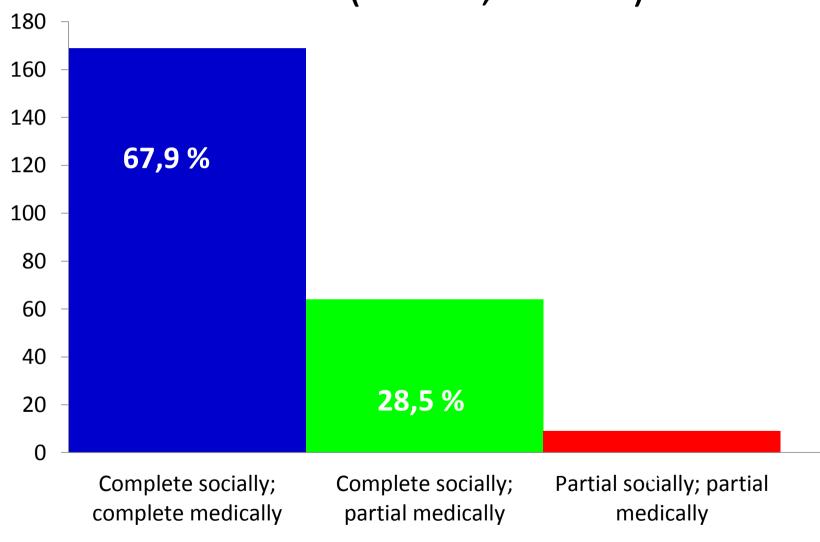
Effects of legal changes

Atypical treatment requests



## Desire for Type of Treatment in 2013

(adults; N=249)



Beek et al, 2015



### Do we know enough?

First results look promising





#### What is Needed?

- More long-term research about
  - Gender development
  - Quality of life (social, psychological)
  - Physical development (growth, bones, brains)
- Preservation of fertility
- Eligibility criteria (age?)



# What is Needed? (2)

- Cross-clinic, cross-national studies
- Networks of researchers (Adolescent Gender Identity Research Group; AGIR)
- Fundamental research AND clinical research



## Find The Right Balance Between Caution And Willingness To Move Forward

