

# Transition to the adult care - the Helsinki model

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# Pediatric kidney transplantation in Finland

- Finland's population is about 5,5milj
- 5 University Hospitals
- 22 Central Hospitals
- All pediatric solid organ transplantation evaluations, transplant operations and long term follow-up are centralized in Helsinki at The Children's Hospital

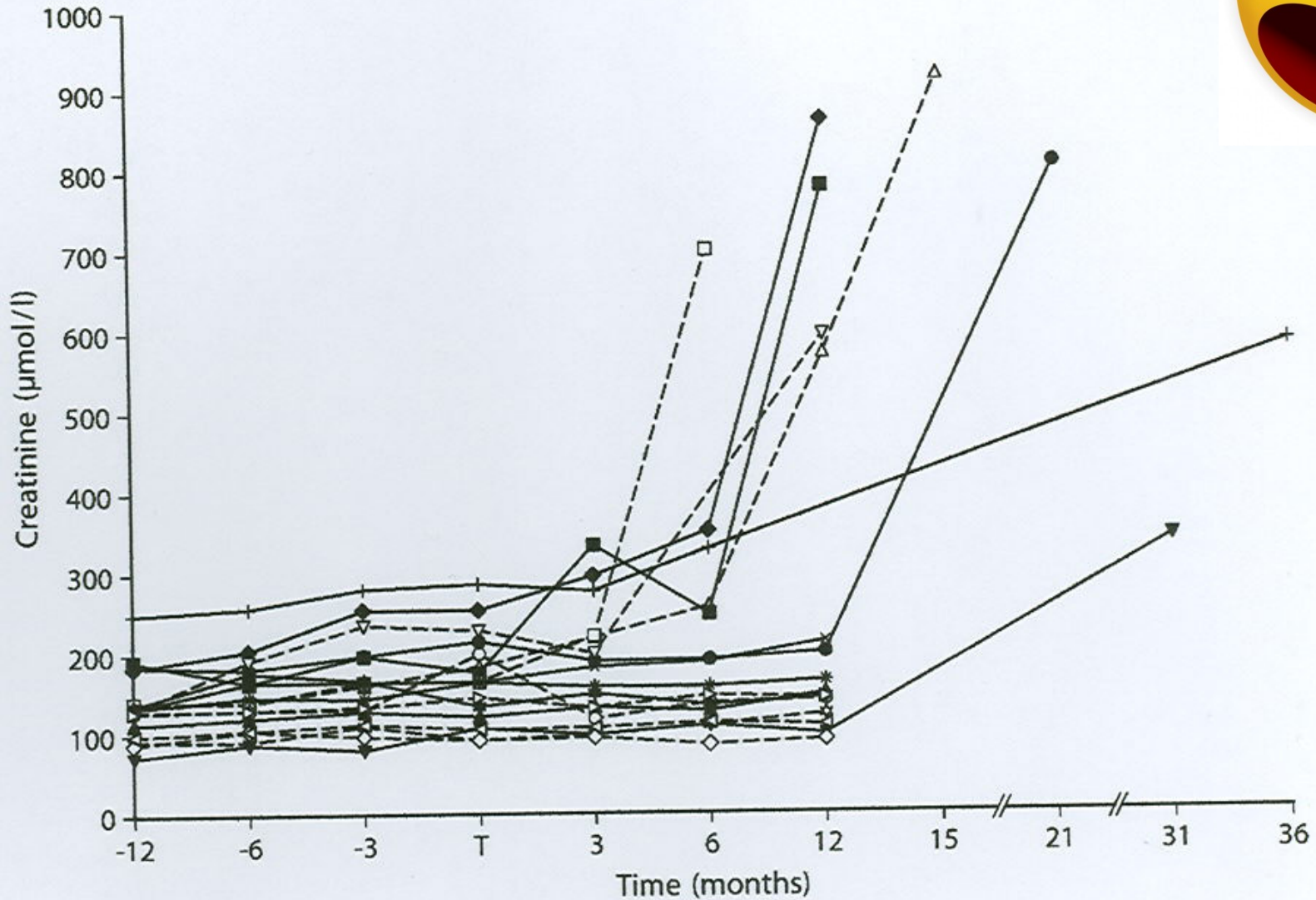
# Kidney transplantations at The Childrens Hospital since 1986

- 249 children have been kidney tx
- The mean age in kidney transplantations is about 5 years
- Many adolescents do not remember their pre-transplant period or the transplantation!
- 148 transferred to the adult care

# Follow-up after transplantation

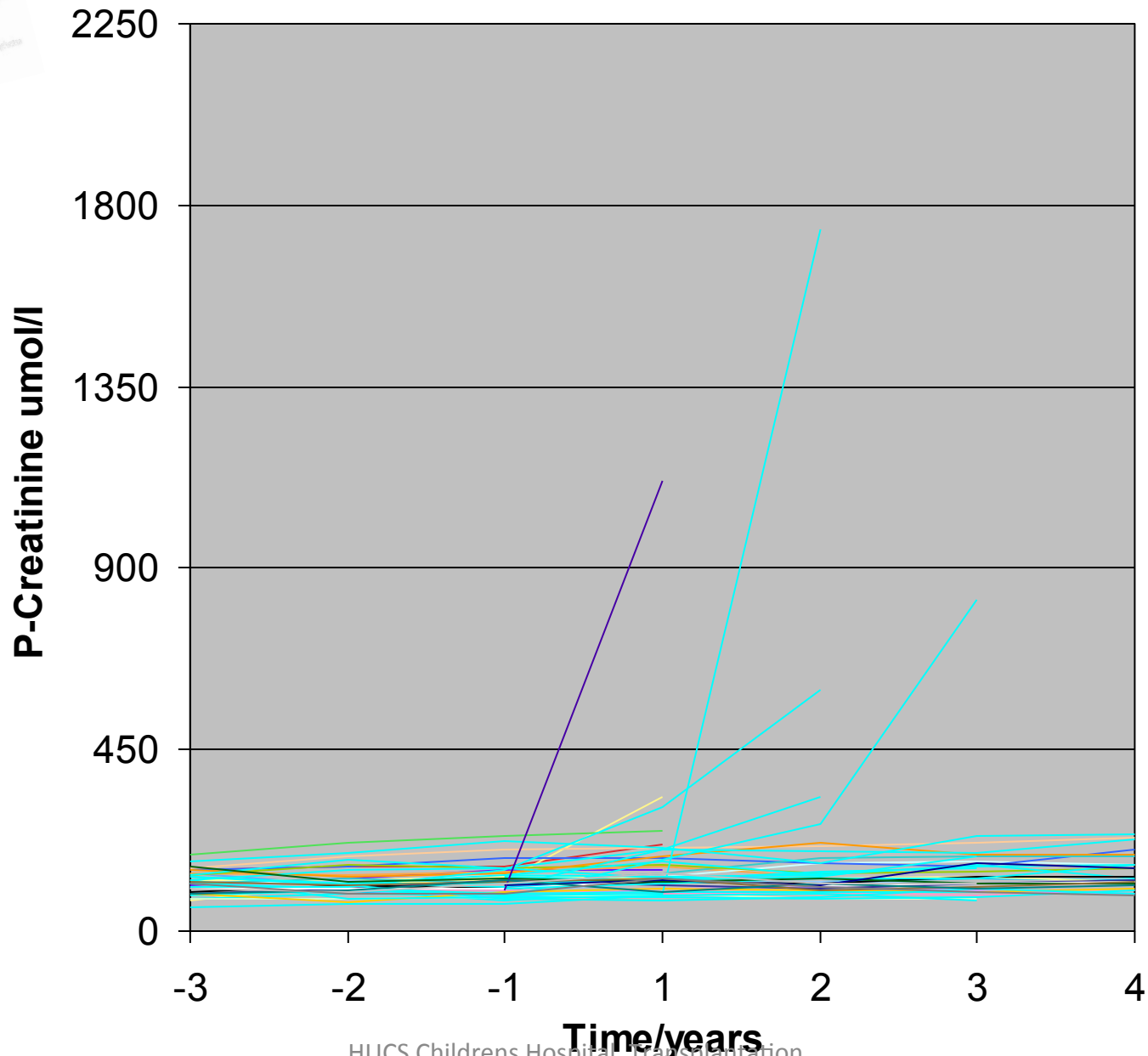
- Pediatric care
  - at least once per year in the transplantation unit in The Children's Hospital in Helsinki
  - other controls (at least every 2 month) in the local Central Hospitals and / or at the patients "home" University Hospital
  - in Finland we have no prescribed age for transferring patients to the adult care
  - usually between 18-20 years of age
- Adult care
  - Follow-up only at the patients own Central Hospital

# WHAT?!





.. also in Finland!!



HUCS Childrens Hospital, Transplantation office

# A young kidney recipient

- risk to die in the age of 18-24 year is double compared to the mortality of 12-17 year old
- for adolescents and young adults the risk to lose their kidney transplant one year after transplant is bigger than in any other age group
  - tx in the age of 12-16 y, 10 y-survival 50 %
  - tx in the age of 1-3 y, 10-y survival 85 %
  - the reason is non compliance

- 32 % of young kidney transplant patients are non adherent
- 44 % of graft loss was due to non-compliance
- if there has been non compliance as child it often continues on the adult side
- there are non adherent adolescents, who become adherent when on the adult side



# Arrangements for a better transition

- When does transition begin?
- Documentation as pictures, diaries
- Talk and tell and share and ask...
- At 7 year of age, alone with the nurse for measurements
- At 10 year of age alone to the doctor a while before parents are invited in
- When puberty starts, transfer to the adolescents outpatient

# Adolescent outpatient clinic

- Started 10 years ago
- The aim is to create a successful transition to adult care
- Situated apart from other outpatient area
- Consulting hours longer per patient



# Adolescent outpatient clinic

- Together with the psychiatric team
- List of subjects to be discussed
- Support to independency and activity
- Information about adult follow-up practice



## Förteckning över de ärenden som diskuteras med den unga

1. Grundsjukdom
2. Dialysskedet
  1. Peritonealdialys
  2. Hemodialys
3. Transplantation
4. Tiden efter transplantationen
5. Mediciner som förhindrar frånstötning
  1. verkningsmekanismerna
  2. biverkningarna
  3. laboratorieprov av medicinkoncentrationerna
  4. om medicinen tas försenat eller blir glömd
  5. medicinernas samverkan
6. Övrig medicinering
7. Uremi
  1. betydelsen av diet
  2. betydelsen av medicinering
  3. betydelsen av dialys
8. Vem ansvarar för medicineringen
9. Infektioner
10. Vaccinationer och resor
11. Betydelsen av kontroller
  1. poliklinikkontroller
  2. avdelningskontroller
12. Vilka laboratorieprov tages och vad berättar de
13. Vilka röntgenundersökningar görs och vad berättar de
14. Biopsier
15. Faktorer som inverkar på det transplanterade organets livslängd
16. Inverkar transplantationen på uppskattad livslängd

17. Alkohol
18. Tobak, snus, droger
19. Sällskapande, äktenskap, familj
20. Presentation av ungdomsgynekologens tjänster
21. Sexuallivet
22. Prevention och preventionsrådgivning
23. Hobbyn
24. Motion
25. Förbundets ungdomsverksamhet
26. Skola och yrkesval
27. Armé, uppååd, intyg
28. Presentation av ungdomspsykiatern
29. Förflyttning till vuxensidan
30. Tatuering / piercing
31. Födelsemärken, hudvård, solbad mm
32. Brun utan sol crème och dusch

Bästa unga, här är förteckningen på de ärenden som vi kommer att behandla på ungdomsmottagningen. Ordningsföljden är fri, och den kan du själv påverka. Tag upp det ärende, som du själv är intresserad av!  
Om du tycker att det fattas någonting viktigt, berätta det åt oss, så kan vi tillsätta det.

# Criteria for transferring

- Final length
- Puberty passed
- Secondary school is finished
- Can independently take care of the medication and control visits
- Adolescent is willing to transfer
- The family is willing to transfer

# CAMP since 2011

- A two day camp for adolescents transferring to the adult care within a year
- Since 2013 many patient groups participate
- Arranged by personnel at The Children's Hospital together with personnel from patient organizations
- Workgroups and discussions with themes that are adequate when becoming an adult and starting to take care of one selves
- Visit to some adult care unit's

# Transferring to the adult side

- Well planned timing!
- Contact with the adult colleagues in charge
- Medical summary and referral is made
- If problematic cases we have a meeting among colleagues in advance
- Before 2011 even mixed-meeting at the first outpatient visit at the adult clinic with representatives from the Children's Hospital and the adult Hospital together with the transferring patient

# Requrements from the adult side

During the first 1 - 2 years:

- control visits more frequent; every 2 - 3 months
- the same nephrologist and nurse meet the young adult
- to arrange possibility to get help from psyc-soc



# Experiences of transition clinics

- Oxford and Lontoo:
  - y. 2000-2006 9 young patients were transferred from the ped.side to the adult side
    - 33 % got an acute rejection and 6/9 lost their transplant (1-62 kk)
  - y. 2006-2010 12 young patients through the transition clinic
  - no acute rejections or lost of transplants (18-60 kk)

# Experiences of transition clinics

- In Canada:
  - before 2007 with out a transition clinic
    - 8/33 (24%) lost their transplant (7) or died (3) with in 24 months
  - after 2007 12 young through the transition clinic
    - no one lost their transplant or died with in 24 months

*Thank You!*

