

# Registo da DRC5 em TSFR 2021



SPNP

Sociedade Portuguesa  
de Nefrologia Pediátrica

- Conceição Mota (CHUPorto)
- Rosário Stone (H.S. Maria, Lisboa)
- Margarida Abranches (H. D. Estefânia, Lisboa)
- Clara Gomes (H. Pediátrico de Coimbra)



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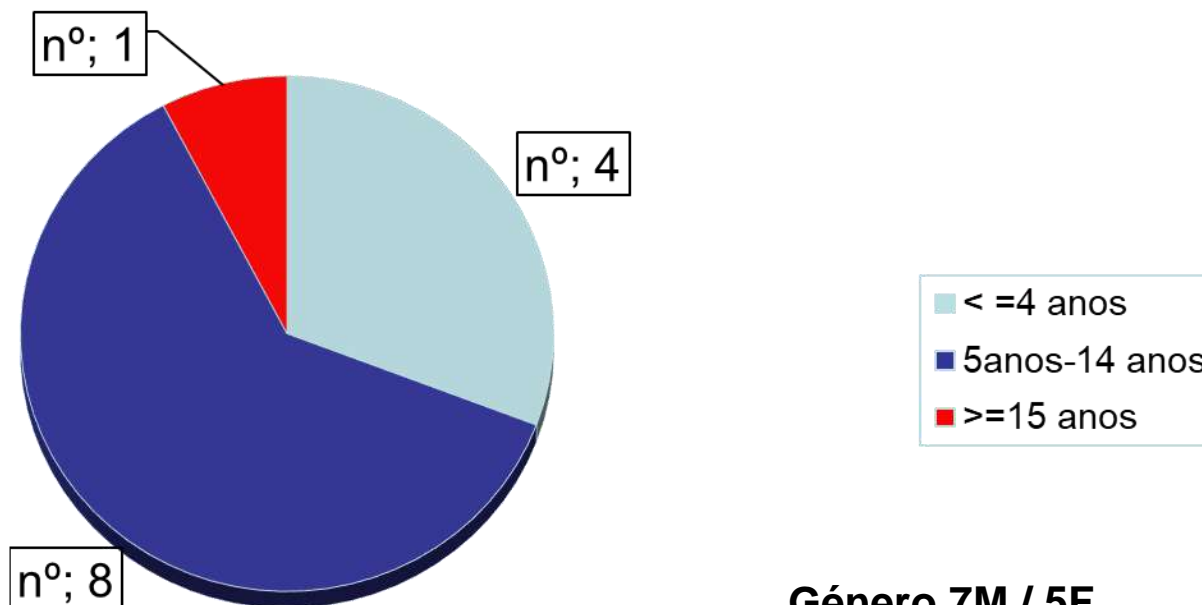
Sociedade Portuguesa  
de Nefrologia Pediátrica

**Dados de 2021**

# Doentes Incidentes em 2021 (1º TSFR)

12 doentes

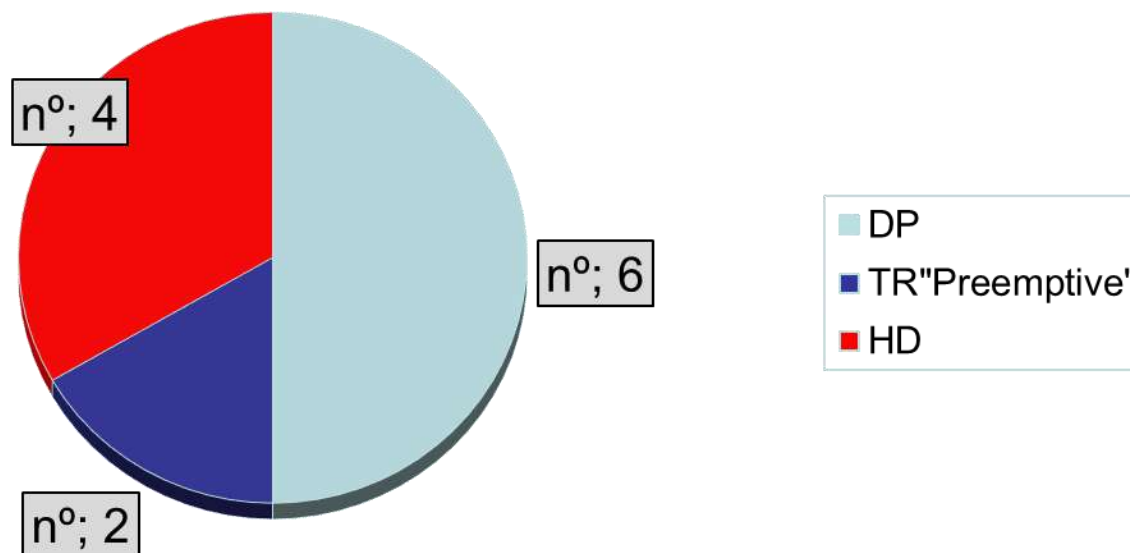
Idade Média = 9,1 anos (min.1 ano; máx. 17anos)



**Género 7M / 5F**

**Raça: 9 caucasianos / 3 outros**

# Primeiro TSFR

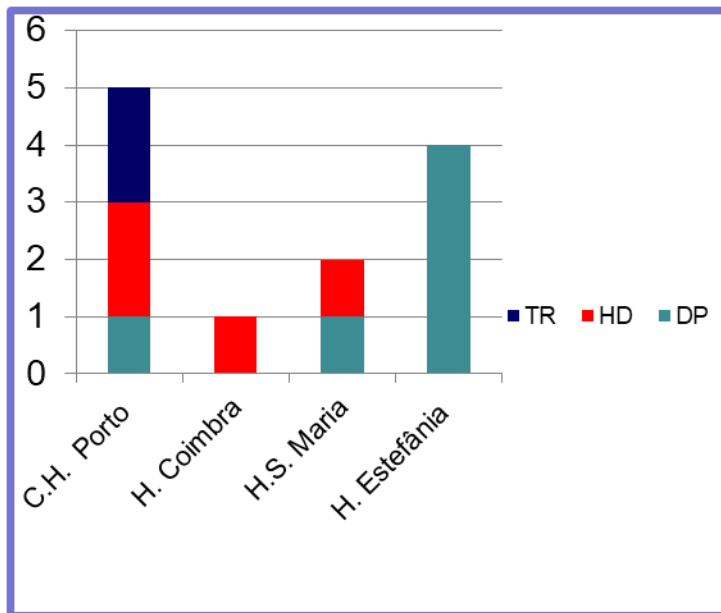


# Novos Doentes na Unidade

## TSFR na admissão da Unidade

-ano 2021-

N=12 → D1 de TSFR



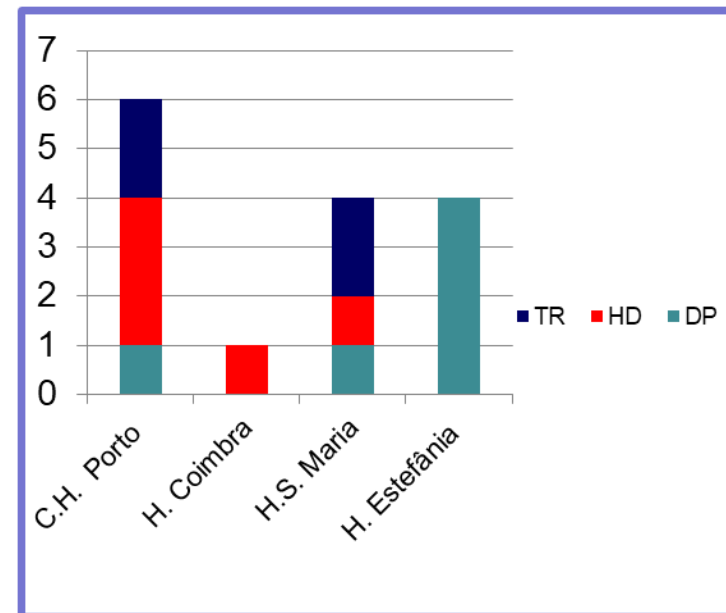
N=15 (12 incidentes+ 3 outras Unidades)

### Doentes em TSFR

#### transferidos:

2 HD Estefânia → S Maria -TR

1 HD (Angola) → CHPorto



# Doentes pediátricos que foram transplantados

**2021**

**N=13 transplantes**

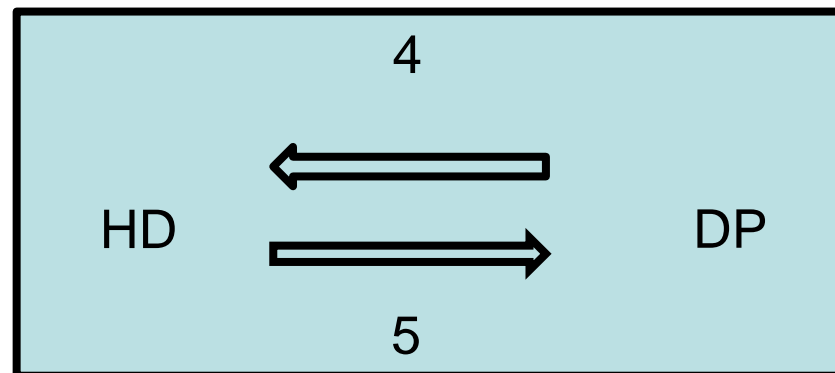
- **Centro Hospitalar do Porto; n=9**
  - **H. S. Maria, CH Lisboa Norte; n=3**
  - **H. P. Coimbra; n=1**
- 
- Dador: Rim de dador cadáver n=12; dador vivo n=1
  - TR *préemptive* n= 2

<b>ENTRADAS</b>	
Incidentes em TSFR (D1 TSFR)	12

# Movimento - Ano de 2021 -



<b>MOVIMENTO</b>	
Número de TR	13
Mortos	2
Recuperação da FR	0
Saída de registo → transferência “Adultos”	18





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## **Prevalência pontual de doentes em TSFR em ambiente pediátrico**

**-31/12/2021-**

**N=97**

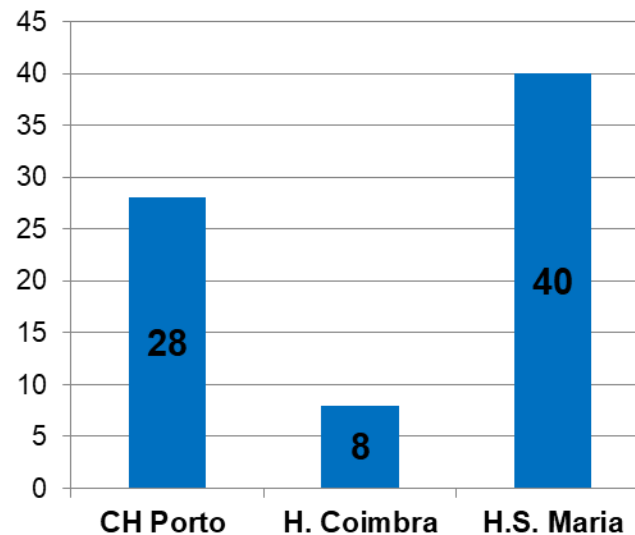
- **TR funcionante = 76 (78,4%)**
- **Diálise = 21 (21,6%)**



# Prevalência pontual de doentes com transplante renal (enxerto funcionante) em ambiente pediátrico

31/12/2021

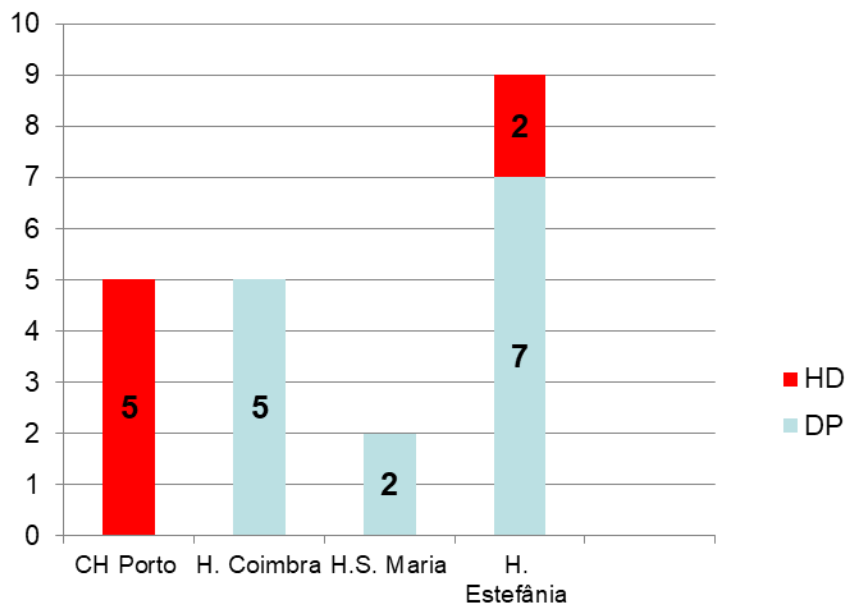
N = 76



# Prevalência pontual de doentes em diálise em ambiente pediátrico

31/12/2021

N = 21



DP = 14 (66,6%)  
HD = 7 (33,3%)

# **Evolução**

## **Registo 2007-2021**

### **291 doentes inseridos**

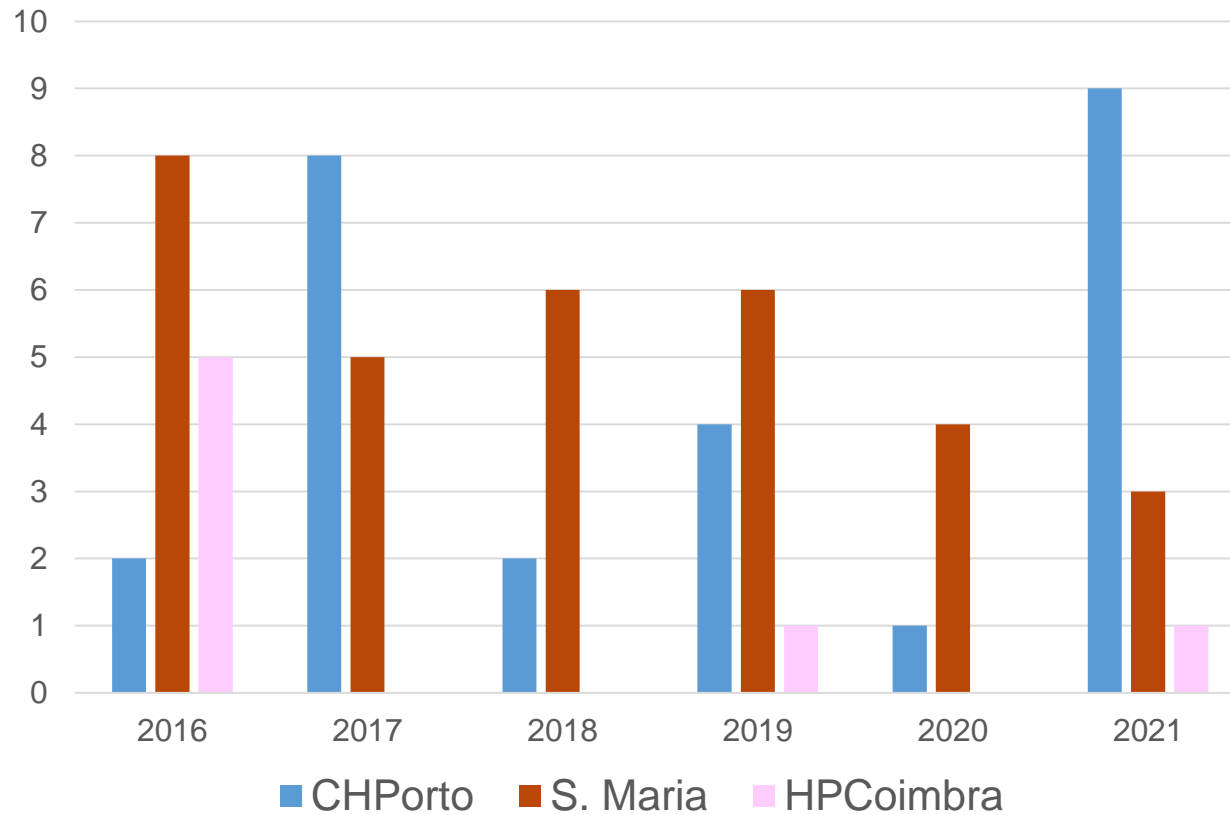
## Ano 2007-2021:

**Total doentes incidentes- 213**  
**Média: 15,2 doentes incidentes/ano**

**Total TR - 206**  
**Média: 14,7 TR/ano**

Ano	Incidentes 1ªTSFR	Transplante/ ano
2007	19	17
2008	16	18
2009	18	16
2010	17	17
2011	18	16
2012	24	17
2013	10	17
2014	17	7
2015	16	20
2016	11	15
2017	13	13
2018	14	6
2019	15	10
2020	9	5
2021	12	13

# Nº TR/ano Unidade CR\_TR\_Pediátrico → ano 2016



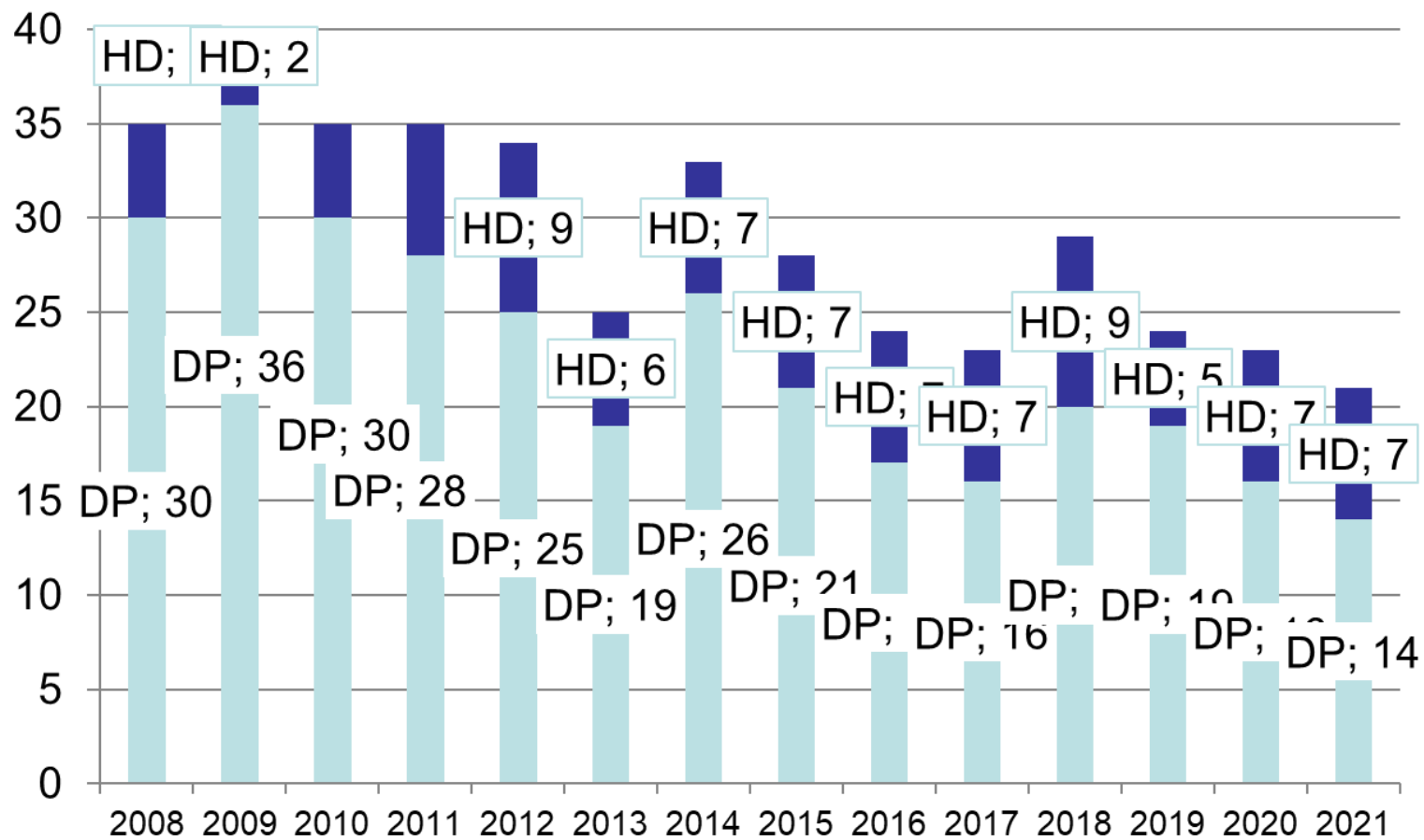
Total

26

32

7

## Prevalência pontual de doentes em diálise a 31 de Dezembro





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https://spp.pt/conteudos/default.asp?ID=430

- › Cuidados Intensivos Pediátricos
- › Doenças Hereditárias do Metabolismo
- › Endocrinologia e Diabetologia Pediátrica
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- › Agenda e Notícias
- › Neonatologia
- › Pediatria Ambulatória
- › Pediátrica da Qualidade e Segurança do Doente
- › Pediátrica de Imunodeficiências Primárias
- › Pediatria do Neurodesenvolvimento
- › Pediatria Social
- › Pneumologia Pediátrica e do Sono
- › Reumatologia Pediátrica

### Registo IRCT

(Registo dos doentes em tratamento substitutivo renal (TSR) seguidos nas Unidades Pediátricas em Portugal)

Registo IRCT 2020	(3451KB)
Registo IRCT 2019	(1742KB)
Registo IRCT 2018	(475KB)
Registo IRCT 2017	(1527 KB)
Registo IRCT 2016	(810 KB)
Registo IRCT 2015	(1140 KB)
Registo IRCT 2014	(904 KB)
Registo IRCT 2013	(258 KB)
Registo IRCT 2012	(206 KB)
Registo IRCT 2011	(260KB)
Registo IRCT 2010	(264KB)
Registo IRCT 2009	(1956KB)
Registo IRCT 2008	(1263KB)
Registo IRCT 2007	(1216KB)



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European  
society for  
paediatric  
nephrology

# ESPN/ERA-EDTA Registry

Registry of the European Society for Paediatric Nephrology and the European Renal Association and European Dialysis and Transplantation Association



ESPN <http://espn.cardiff.ac.uk> ESPN/ERA-EDTA Registry <http://www.espn-reg.org>

Início ano 2007

>24 000 doentes individuais

40 países

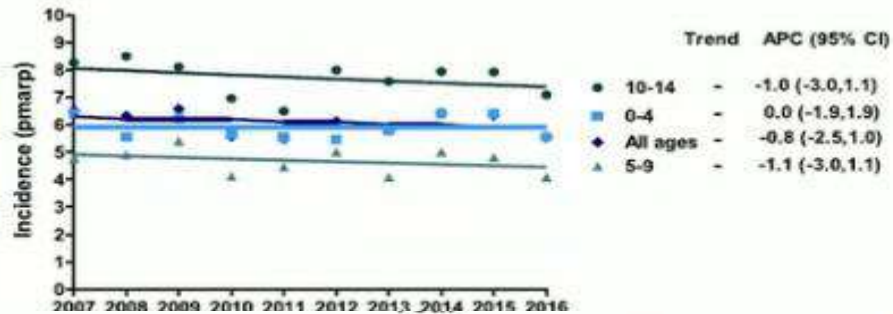


# Epidemiology

## Children 0-14 years old

### Incidence of KRT

Stable incidence of KRT  
over 10 years: ~ 6 pmc in  
children < 15 years

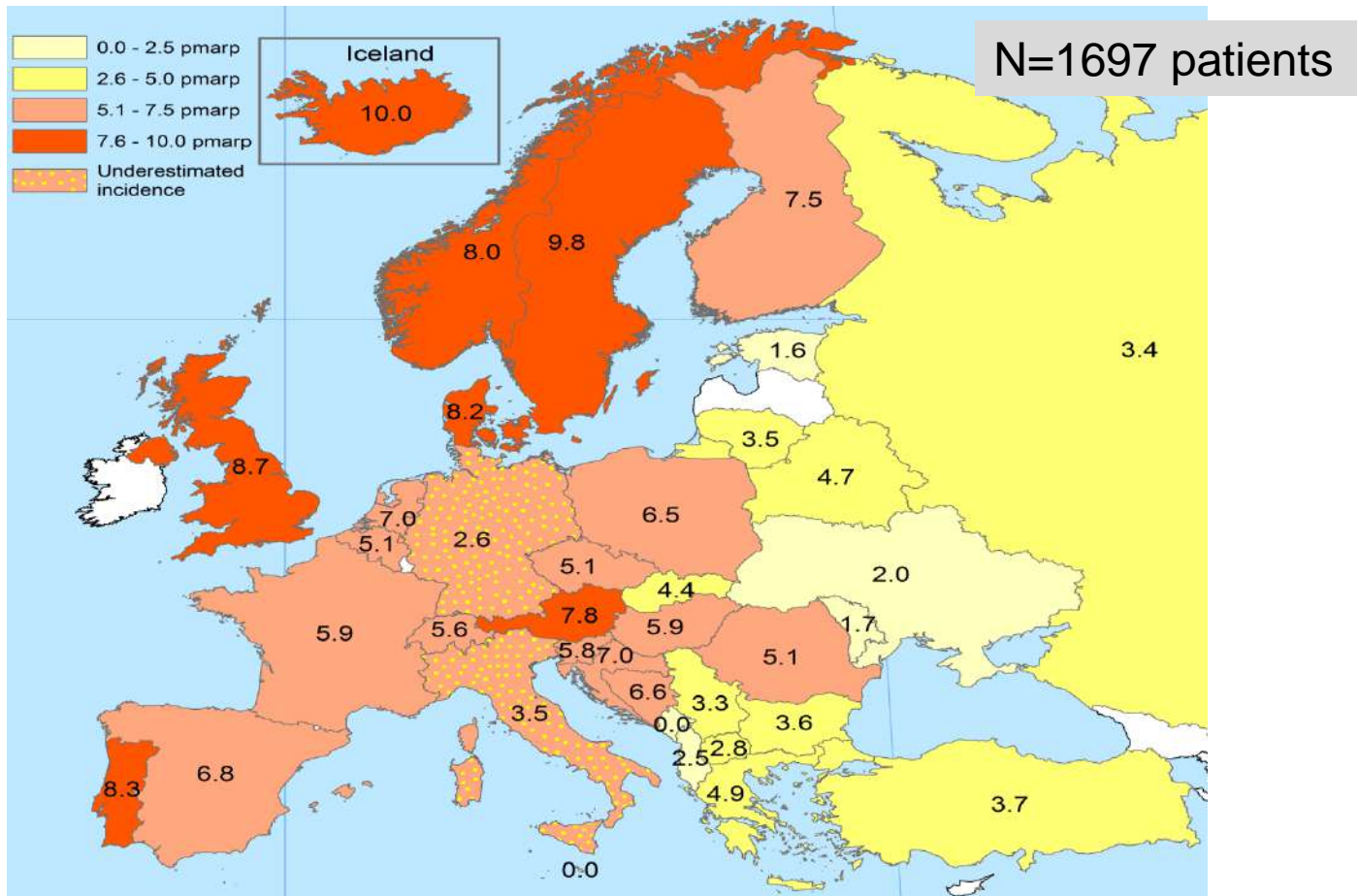


22 countries



Bonthuis, Ped Nephrol (2021)

# Variable incidence in Europe



Demographics of paediatric renal replacement therapy in Europe: a report of the ESPN/ERA-EDTA registry.

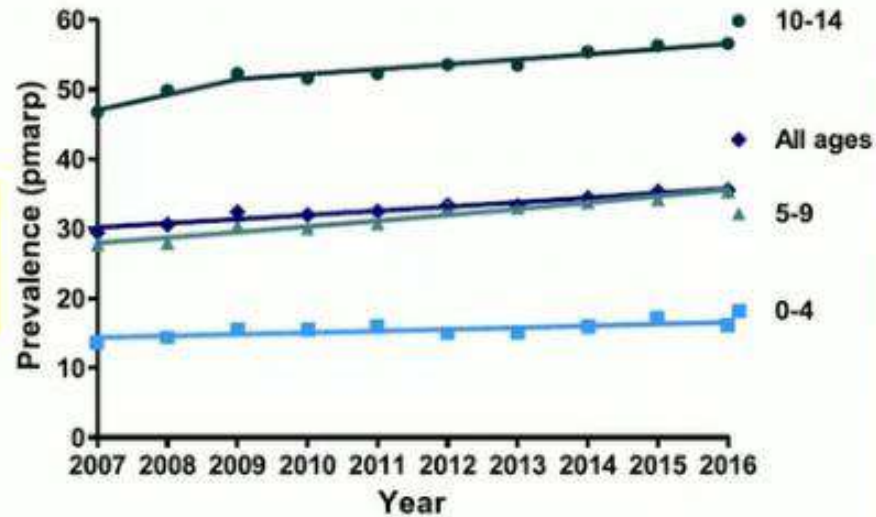
Chesnaye N, Nephrol Dial Transp 2015

# Incidência de doentes com idade pediátrica em TSFR



# Prevalence of KRT

Increasing prevalence of KRT over 10 years (2%/yr): ~ 35 pmc in children < 15 years



Bonthuis, Pediatr Nephrol 2021



N=4459  
Children 0-14 years old  
22 countries



Bonthuis, Ped Nephrol (2021)

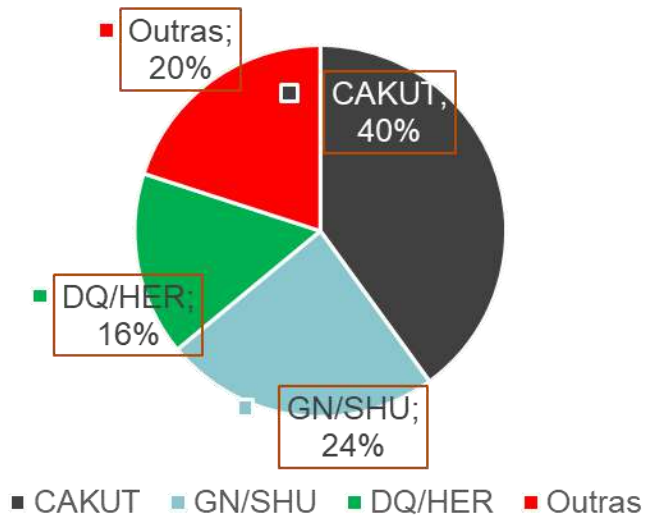
## Prevalência pontual de Doentes Pediátricos em TSFR (0-14 anos)

Ano	Prevalência <sup>1)</sup> p <sub>mart</sub> Europa	Prevalência p <sub>mart</sub> Portugal
31/12/2007	29,4	38,2
31/12/2008	30,0	40,9
31/12/2009	32,4	46,9
31/12/2010	32,0	45,4
31/12/2011	32,5	50,5
31/12/2012	33,4	59,6
31/12/2013	33,5	54,7
31/12/2014	34,4	57,1
31/12/2015	35,3	56,3
31/12/2016	35,6	50,3
31/12/2017	35,1	51,6
31/12/2018	35,2	51,6
31/12/2019	35,5	46,4
21/12/2020	ND	47,5
21/12/2021	ND	46,5

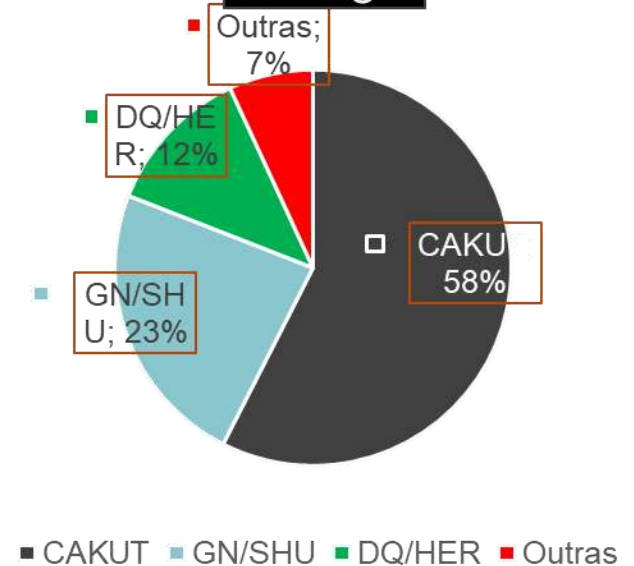
Média 49,7 p<sub>mart</sub>

# Causes of kidney failure

ESPN-ERA/EDTA



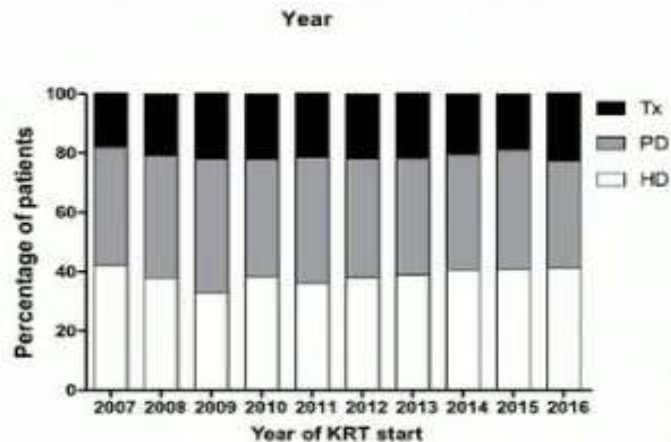
Portugal



# Modality of the first KRT

N=4459  
Children 0-14 years old  
22 countries

Modality at start of KRT:  
40% HD, 40% PD, 20% Tx

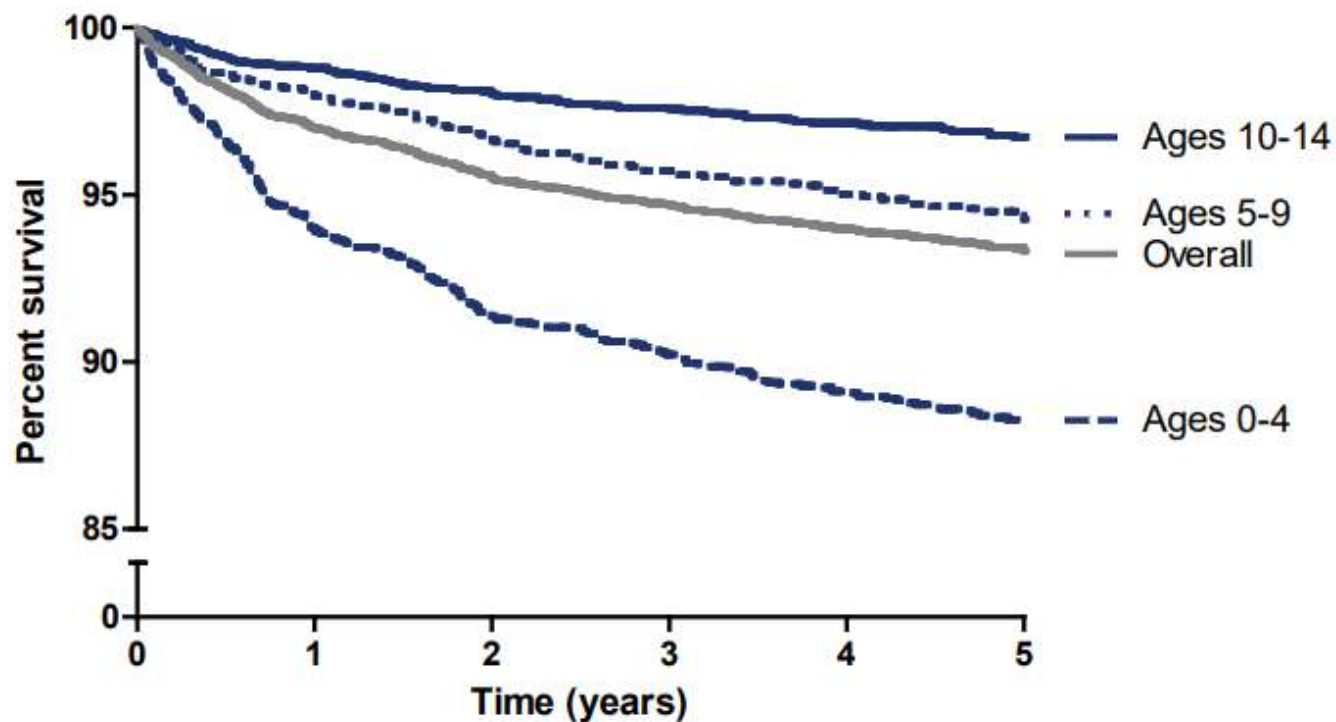


Bonthuis, Pediatr  
Nephrol 2021

**Portugal**  
Incident 2007-2021; N=292  
Modality at start  
83,1% PD ; 8,4%HD ; 8,5%Tx *preemptive*

## Figure 1: Five-year patient survival

Incident KRT patients under the age of 15 starting KRT from 2007 onwards. Follow-up till 31<sup>st</sup> of December 2019.

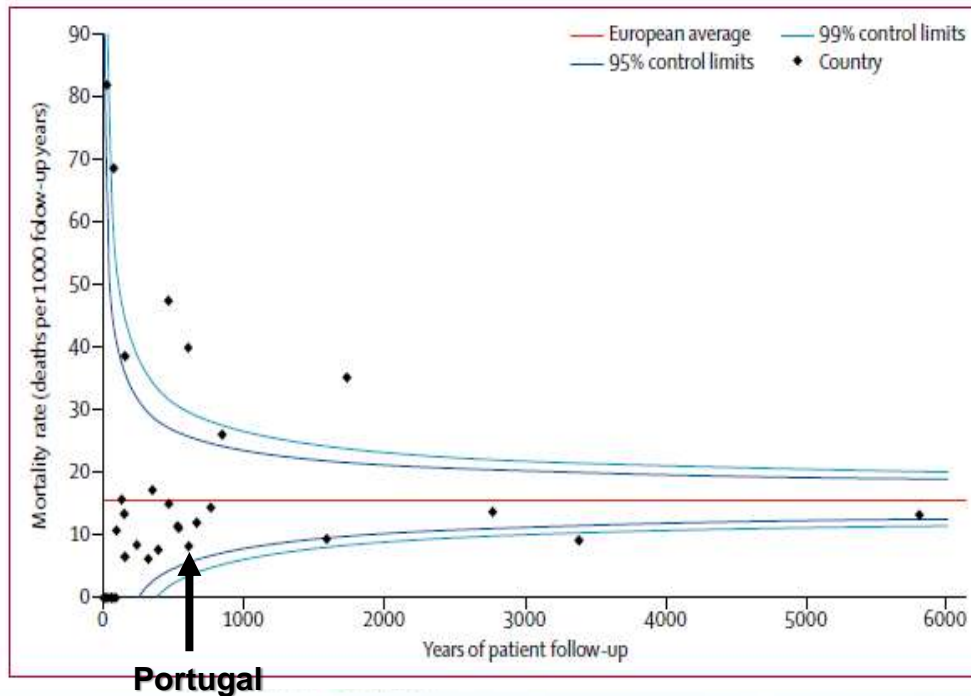


Five-year patient survival was good, around 94%. It was unchanged over time



# Country-specific KRT mortality rate

RRT mortality rate was 15,8 deaths per 1000 follow-up years



Chesnaye et al, Lancet 2017

# Publicações da ESPN/ERA-EDTA

## (coautoria nefrologistas pediátricos portugueses)

1. [Determinants of eGFR at start of renal replacement therapy in paediatric patients.](#) Tizard EJ, Jager KJ, Schaefer F, Vondrak K, Groothoff JW, Podracká L, Holmberg C, Jankauskiené A, Lewis MA, van Damme-Lombaerts R, **Mota C**, Niaudet P, Novljan G, Peco-Antic A, Sahpazova E, Toots U, Verrina E. . *Nephrol Dial Transplant*. 2010 Oct;25(10):3325-32.
2. [Underweight, overweight and obesity in paediatric dialysis and renal transplant patients.](#) Bonthuis M, van Stralen KJ, Verrina E, Groothoff JW, Alonso Melgar A, Edefonti A, Fischbach M, **Mendes P**, Molchanova EA, Paripović D, Peco-Antic A, Printza N, Rees L, Rubik J, Stefanidis CJ, Sinha MD, Zagozdzon I, Jager KJ, Schaefer F; *NDT* 2013; 0:1-10
3. [Demographics of paediatric renal replacement therapy in Europe: a report of the ESPN/ERA-EDTA registry.](#) Chesnaye N, Bonthuis M, Schaefer F, Groothoff JW, Verrina E, Heaf JG, Jankauskiene A, Lukosiene V, Molchanova EA, **Mota C**, Peco-Antić A, Ratsch IM, Bjerre A, Roussinov DL, Sukalo A, Topaloglu R, Van Hoeck K, Zagozdzon I, Jager KJ, Van Stralen KJ; on behalf of the ESPN/ERA-EDTA registry. *Pediatr Nephrol*. 2014 Jul 21.
4. [Adult height in patients with advanced CKD requiring renal replacement therapy during childhood.](#) Harambat J, Bonthuis M, van Stralen KJ, Ariceta G, Battelino N, Bjerre A, Jahnukainen T, Leroy V, Reusz G, **Sandes AR**, Sinha MD, Groothoff JW, Combe C, Jager KJ, Verrina E, Schaefer F; ESPN/ERA-EDTA Registry. *Clin J Am Soc Nephrol*. 2014 Jan;9(1):92-9.

# Publicações da ESPN/ERA-EDTA (coautoria de nefrologistas portugueses)

5. **Mineral metabolism in European children living with a renal transplant: a European society for paediatric nephrology/european renal association-European dialysis and transplant association registry study.**  
[Bonthuis M](#), [Busutti M](#), [van Stralen KJ](#), [Jager KJ](#), [Baiko S](#), [Bakkaloğlu S](#), [Battelino N](#), [Gaydarova M](#), [Gianoglio B](#), [Parvex P](#), [Gomes C](#), [Heaf JG](#), [Podracka L](#), [Kuzmanovska D](#), [Molchanova MS](#), [Pankratenko TE](#), [Papachristou F](#), [Reusz G](#), [Sanahuja MJ](#), [Shroff R](#), [Groothoff JW](#), [Schaefer F](#), [Verrina E](#). *Clin J Am Soc Nephrol*. 2015 May 7;10(5):767-75. doi: 10.2215/CJN.06200614.
6. **Considerable variations in growth hormone policy and prescription in paediatric end-stage renal disease across European countries-a report from the ESPN/ERA-EDTA registry.**  
[van Huis M](#), [Bonthuis M](#), [Sahpazova E](#), [Mencarelli F](#), [Spasojević B](#), [Reusz G](#), [Caldas-Afonso A](#), [Bjerre A](#), [Baiko S](#), [Vondrak K](#), [Molchanova EA](#), [Kolvek G](#), [Zaikova N](#), [Böhm M](#), [Ariceta G](#), [Jager KJ](#), [Schaefer F](#)<sup>1</sup>, [van Stralen KJ](#), [Groothoff JW](#). *Nephrol Dial Transplant*. 2015 Apr 28. pii: gfv105.
7. **Infants requiring maintenance dialysis: outcomes hemodialysis and peritoneal dialysis.** [Vidal E](#), [van Stralen KJ](#), [Chesnaye NC](#), [Bonthuis M](#), [Holmberg C](#), [Zurowska A](#), [Trivelli A](#), [José Eduardo Esteves da Silva J](#), [Herthelius M](#), [Adams B](#), [Bjerre A](#), [Jankauskiene A](#), [Miteva P](#), [Emirova K](#), [Bayazit AK](#), [Mache JC](#), [Sánchez-Moreno A](#), [Harambat J](#), [Groothoff JW](#), [Jager KJ](#), [van Stralen KJ](#), [Bonthuis M](#), [Groothoff JW](#), [Harambat J](#), [Schaefer F](#), [Verrina E](#). *Am J Kidney Dis*. 2017 May;69(5):617-625.
8. **Mortality risk disparities in children receiving renal replacement therapy for the treatment of end-stage renal disease across Europe. An ESPN/ERA-EDTA Registry analysis.** [Chesnaye NC](#), [Schaefer F](#), [Bonthuis M](#), [Holman R](#), [Baiko S](#), [Baskin E](#), [Bjerre A](#), [Cloarec S](#), [Cornelissen EAM](#), [Espinosa L](#), [Heaf JG](#), [Stone R](#), [Shtiza D](#), [Zagozdzon I](#), [Harambat J](#), [Jager KJ](#), [Groothoff JW](#), [van Stralen KJ](#). *Lancet*. 2017 May; 389(10084) :2128-2137.

# Publicações da ESPN/ERA-EDTA (coautoria de nefrologistas portugueses)

9. **Association between timing of dialysis initiation and clinical outcomes in the paediatric population: an ESPN/ERA-EDTA registry study.** [Evgenia Preka](#) , [Marjolein Bonthuis](#) , [Jerome Harambat](#) , [Kitty J Jager](#) , [Jaap W Groothoff](#) , [Sergey Baikov](#) , [Aysun K Bayazit](#) , [Michael Boehm](#) , [Mirjana Cvetkovic](#) , [Vidar O Edvardsson](#) , [Svitlana Fomina](#) , [James G Heaf](#) , [Tuula Holttä](#) , [Eva Kis](#) , [Gabriel Kolvek](#) , [Linda Koster-Kamphuis](#) , [Elena A Molchanova](#) , [Marina Muñoz](#) , [Gisela Neto](#) , [Gregor Novljan](#) , [Nikoleta Printza](#) , [Emilija Sahpazova](#) , [Lisa Sartz](#) , [Manish D Sinha](#) , [Enrico Vidal](#) , [Karel Vondrak](#) , [Isabelle Vrillon](#) , [Lutz T Weber](#) , [Marcus Weitz](#) , [Ilona Zagozdzon](#) , [Constantinos J Stefanidis](#) , [Sevcan A Bakaloglu](#). *Nephrol Dial Transplant*. 2019 ; Nov 1;34(11):1932-1940.
10. **Results in the ESPN/ERA-EDTA Registry suggest disparities in access to kidney transplantation but little variation in graft survival of children across Europe** [Marjolein Bonthuis](#) , [Liz Cuperus](#) , [Nicholas C. Chesnaye](#) , [Sema Akman](#) , [Angel Alonso Melgar](#) , [Sergey Baikov](#) , [Antonia H. Bouts](#) , [Olivia Boyer](#) , [Kremena Dimitrova](#) , [Carmen do Carmo](#) , [Ryszard Grenda](#) , [James Heaf](#) , [Timo Jahnukainen](#) , [Augustina Jankauskiene](#) , [Lukas Kaltenecker](#) , [Mirjana Kostic](#) , [Stephen D. Marks](#) , [Andromachi Mitsioni](#) , [Gregor Novljan](#) , [Runolfur Palsson](#) , [Paloma Parvex](#) , [Ludmila Podracka](#) , [Anna Bjerre](#) , [Tomas Seeman](#) , [Jasna Slavicek](#) , [Tamas Szabo](#) , [Burkhard Tonshoff](#) , [Diletta D. Torres](#) , [Koen J. Van Hoeck](#) , [Susanne Westphal Ladfors](#) , [Jerome Harambat](#) , [Jaap W. Groothoff](#) and [Kitty J. Jager](#). *Kidney International* *Kidney International* 2020 ;98, 464–47
11. **Growth patterns after kidney transplantation in European children over the past 25 years: An ESPN/ERA-EDTA Registry study.** [Bonthuis M](#) , [Groothoff JW](#) , [Ariceta G](#) , [Baikov S](#) , [Battellino N](#) , [Bjerre A](#) , [Cransberg K](#) , [Kolvek G](#) , [Maxwell H](#) , [Miteva P](#) , [Molchanova MS](#) , [Neuhaus TJ](#) , [Pape L](#) , [Reusz G](#) , [Rousset-Rouviere C](#) , [Sandes AR](#) , [Topaloglu R](#) , [van Dyck M](#) , [Ylinen E](#) , [Zagozdzon I](#) , [Jager KJ](#) , [Harambat J](#). *Transplantation* 2020; 104(1):137-144.
12. **Comorbidities. Disparities in treatment and outcome of kidney replacement therapy in children with comorbidities: An ESPN/ERA-EDTA Registry study.** [Raphael Schild\\*](#) , [Simeon Dupont\\*](#) , [Jérôme Harambat](#) , [Enrico Vidal](#) , [Ayşe Balat](#) , [Csaba Berecki](#) , [Beata Bieniasz](#) , [Per Brandström](#) , [Francoise Broux](#) , [Silvia Consolo](#) , [Ivana Gojkovic](#) , [Jaap W. Groothoff](#) , [James G. Heaf](#) , [Holger Hubmann](#) , [Shaun Mannings](#) , [Tatiana E. Pankratenko](#) , [Fotios Papachristou](#) , [Lucy A. Plumb](#) , [Ludmila Podracka](#) , [Sylwester Prokurat](#) , [Anna V. Reisaeter](#) , [Carolina Cordinhã](#) , [Paula Seikku](#) , [Enkeledja Shkurti](#) , [Giuseppina Sparta](#) , [Karel Vondrak](#) , [Kitty J. Jager](#) , [Jun Oh](#) , [Marjolein Bonthuis](#). For submission to *Clinical Journal of the American Society of Nephrology*.



Conceição Mota  
Rosário Stone  
Margarida Abranches  
Clara Gomes  
Helena Jardim