



3.7.9 Research on Comprehensive Care for Transplanted Children and Adolescents

1 Introduction

2 Executive summary

3 Research areas and groups

4 Associated clinicians



Publications: 7 | QI: 6

COMPOSITION

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STRATEGIC OBJETIVES

- Pediatric solid organ transplantation (SOT) and hematopoietic stem cell transplantation (HSCT) have dramatically changed the life expectancy of many children by providing them with treatment they would not otherwise have survived. Worldwide, approximately 150,000 hematopoietic stem cell transplants and 80,000 hematopoietic stem cell transplants are performed annually. Pediatric transplantation accounts for about 10% of all SOTs and 20% of all HSCTs. Between 2012 and 2016, 7,741 SOTs and 14,717 HSCTs were performed in children in the European Union (EU), and the number of transplants performed worldwide continues to rise.
- Pediatric SOT and HSCT replace terminal illness with a more sustainable chronic condition, enabling young people to reach adulthood. However, while transplantation can improve individual health outcomes, it can also be associated with long-term side effects requiring ongoing monitoring and care. Post-transplant follow-up care aims to prevent rejection and transplant-related complications so that each individual can achieve a life expectancy and quality of life (QoL) similar to that of their healthy peers.
- The "Research in comprehensive care for transplanted children and adolescents" group arises from the need to fill the gaps in knowledge about comprehensive care for children and adolescents who receive transplants in the pediatric age.
- The group will focus on researching three specific topics:
 1. Transition and transfer of adolescents and young adults (AYAs) living with a transplant to adult clinics: clinical and psychosocial impact. Transition is a gradual, multifaceted, active, and intentional process involving many important steps and checkpoints. The process consists of three phases: (1) transition planning and preparation, (2) transfer of care, and (3) integration into adult healthcare. Each of these phases presents unique obstacles to success and opportunities for improvement.
 2. Quality of life in the context of pediatric transplantation: patient-reported outcomes and experience measures (PROM and PREM).
 3. Innovation in health education for transplanted children and adolescents and their parents/caregivers/relatives: evaluation of programs and validation of tools and questionnaires.

RESEARCH LINES

- Transition and transfer of adolescent and young adult pediatric transplant recipients to adult care: clinical and psychosocial impact.
- Quality of life in pediatric transplantation: outcome measures and experiences reported by the patient/family (PROMs and PREMs).
- Innovation in health education for transplanted children and adolescents and their parents/caregivers/family: evaluation of programs and validation of tools and questionnaires.

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RESEARCH ACTIVITY



Master Theses

- **Marcos Blasco A, Fierro Castillo C.** Satisfacción familiar con un Programa de Acogida de pacientes pediátricos en espera de trasplante de órgano sólido.[dissertation]. Madrid: UAM: 2025(30/04/2025). Director: Pascau González-Garzón MJ, Martínez Campos P.

Publications

- **Alba-Cano T, Alonso R, Balastegui-Martín H, Bravo-Gallego LY, Sánchez-Mateos P, Martín-**

López M, Gil-Herrera J. Impact of CMV latency on T-cell responses to COVID-19 vaccination among predominantly antibody-deficient patients. *Front Immunol.* 2025; 16: 1659259. Article. IF: 7.0; Q1

- **Amil-Dias J, Kvist PK, Bravo-Gallego LY, Hartmann D, Fracasso P, Suykens J, Tornblom H, Buti M, Dugic A, Torres J, Leone S, Maravic Z, Mishkovikj M, Koltai T, Carboni A, Wickramasinghe K, Alimena L, Burra P.** Transition from youth to adulthood: UEG 2024

roundtable on navigating chronic digestive and liver disease care. *United European Gastroenterol J.* 2025; 13(10): 2093-5. Article. IF: 6.4; Q1

- **del Rosal T, Morillas-Mingorance A, García-Morato MB, Rodríguez-Pena R, Bravo-Gallego LY, Méndez-Echevarría A.** Infectious and inflammatory events in 2 siblings with IRF9 deficiency under immunoglobulin replacement therapy. *J Allergy Clin Immunol.* 2025; 156(5): 1433-5. Letter. IF: 11.7; D1
- **Fulvio G, Marinello D, Zucchi D, Aguilera S, Benachi A, Biller R, Blanco I, Boiteux MC, Borgards P, Brandi ML, Costafreda E, Fonseca JE, Fredi M, Guimaraes V, Iotova V, Lecointe-Artzner E, Lopes AR, Louise S, Nalli C, Olesinska M, Onali M, Papenthin W, Power B, Röhl C, Rousset-Jablonski C, Sturz D, Tincani A, Van Vleuten CJD, Vieira A, Dan DRC, Backer JD, Smulders CD, Dufke A, Frank C, Limongelli G, Lorenz B, Kilpiäinen E, Pascau MJ, Raidt J, Ray-Coquard I, Rimmer R, Schneider H, Van Pal HJD, Yap T, Talarico R, Tani C, Mosca M.** Addressing unmet needs in pregnancy and family planning of people living with rare and low-prevalence diseases: results of the ERN transversal working group on pregnancy and family planning survey. *Reprod Health.* 2025; 22(1): 240. Article. IF: 3.4; Q1
- **González-Torrey A, Reche-Yebra K, Clemente-Bernal A, Serrano YS, Bravo-Gallego LY, López AF, Rodríguez-Pena R, García-Morato MB, López-Granados E, del Pino-Molina L.** Functional insights of an uncommon hypomorphic variant in IL2RG as a monogenic cause of CVID-like disease with antibody deficiency and T CD4 lymphopenia. *Front Immunol.* 2025; 16: 1544863. Article. IF: 7.0; Q1

- **Molina LD, Manzano EM, Gianelli C, Gallego LY, Fernández JB, Acuña P, Serrano YS, Yebra KR, García-Morato MB, Zapardiel ES, Arias-Salgado EG, Pena RR, Butta N, Granados EL.** Effects of two different variants in the MAGT1 gene on B cell subsets, platelet function, and cell glycome composition. *Front Immunol.* 2025; 16: 1547808. Article. IF: 7.0; Q1
- **Zucchi D, Marinello D, Tani C, Fulvio G, Aguilera S, Benachi A, Biller R, Blanco I, Borgards P, Boiteux MC, Brandi ML, Costafreda E, Fonseca JE, Fredi M, Iotova V, Louise S, Nalli C, Onali M, Power B, Rousset-Jablonski C, Sturz D, Tincani A, Vieira A, Capela S, Dan DRC, De Backer J, de Die-Smulders C, Dufke A, Artzner EL, Limongelli G, Lorenz B, Papenthin W, Pascau MJ, Raidt J, Ray-Coquard I, Rimmer R, Roehl C, Schneider H, Yap T, Talarico R, Mosca M.** Pregnancy-related issues in rare and low-prevalence diseases: results of ERN transversal working group on pregnancy and family planning survey. *Orphanet J Rare Dis.* 2025; 20(1): 112. Article. IF: 3.6; Q2

Research projects

- **Martínez Campos P.** Escape room educativo: promoviendo la salud y el bienestar en adolescentes con trasplante de órgano sólido. Colegio Oficial de Enfermería de Madrid (CODEM). 2025-2025. **Managment centre:** CODEM
- **Pascau González-Garzón MJ.** Programa educativo de refuerzo educativo para la transición en trasplante de órgano sólido. Chiesi. 2025-Ongoing. **Managment centre:** FIBHULP