



Curriculum Vitae

Personal information **Ines Alves**

Work experience

1. Employer: European Reference Network for rare bone disorders
 - Start date: 06,2017
 - End date:
 - Position: Patient representative & steering committee member
 - Activities:
 - Country: Italy
2. Employer: EURORDIS
 - Start date: 04,2014
 - End date: 04,2021
 - Position: Volunteer and expert reviewer
 - Activities: Rare 2030
 - Country: France
3. Employer: Beyond Achondroplasia
 - Start date: 04,2013
 - End date: present
 - Position: Founder and Author
 - Activities: Influencer multilingual hub on R&D in achondroplasia, Layperson language papers review
 - Country: Portugal
4. Employer: CVRM
 - Start date: 02,2007
 - End date: 03,2015
 - Position: Head veterinary surgeon
 - Activities: 7 years private practice in large & small animal
 - Country: Portugal
5. Employer: EUPATI Portugal
 - Start date: 04,2017
 - End date: present
 - Position: Founder and Vice President
 - Activities: Communication with national patient organizations and Invited keynote speaker at health events
 - Country: Portugal
6. Employer: ANDO Portugal, National Organization for rare Bone Conditions
 - Start date: 05,2015
 - End date: present
 - Position: Founder and President of the board
 - Activities: Patient organization full activities for families, patients, healthcare professionals and national medicines agency
 - Country: Portugal
7. Employer: ALPE Foundation
 - Start date: 04,2015
 - End date: 03,2019
 - Position: Scientific Adviser
 - Activities: Head of international communications with patient org & leaders, Industry, CROs, research teams and academia
 - Country: Spain
8. Employer: GEMSTONE COST action Co lead in WP Translacional research
 - Start date: 09,2018
 - End date: present
 - Position: Co lead scientific Communication
 - Activities: Patient involvement accelerator in a Academia Research action; Scientific Action communication management
 - Country: Netherlands
9. Employer: European Rare Bone Forum
 - Start date: 06, 2019
 - End date: present
 - Position: ERBF Founder and steering group member
 - Activities: Patient_led forum and networking arena between patient organizations, pharma industry & scientific societies
 - Country: Netherlands
10. Employer: EuRR-BONE, European Registry for Rare bone disorders
 - Start date: 04,2020
 - End date: present
 - Position: Co_chair of Patient Outcomes;
 - Activities: Data set development for study group on achondroplasia
 - Country: Netherlands
11. Employer: Health Parliament Portugal
 - Start date: 09,2019
 - End date: 10,2021
 - Position: Deputy Health Parliament Portugal
 - Activities: Member of the Technology and Care Integration Commission
 - Country: Portugal
12. Employer: H2020, IMI 2

- Start date: 09,2020
 - End date: 10,2020
 - Position: Expert Evaluator
 - Activities: Short proposals Panel evaluation group member
 - Country: Belgium
13. Employer: EUPATI Foundation
- Start date: 10,2020
 - End date: present
 - Position: Trainer for the Fundamentals Training
 - Activities: Pharma and academia Training on Patient engagement
 - Country: Belgium
14. Employer: Patient focused medicines development
- Start date: 04, 2017
 - End date: 05, 2019
 - Position: PFMD Task force member for Compliance and Legal Hurdles task force
 - Activities: PFMD is Patient Focused Medicines Development, in which we take over discussions on critical points to patients
 - Country: Belgium
15. Ad hoc invited evaluator: DLR research agency
- Start date: 04, 2020
 - End date: 30, 2024
 - Position: proposals review board
 - Activities: Patient participation in research proposals
 - Country: Germany
16. Ad hoc invited evaluator: European Joint Program for Rare diseases
- Start date: 01, 2020
 - End date: 10, 2023
 - Position: proposals review board
 - Activities: Patient participation in research proposals
 - Country: France
17. Ad hoc invited evaluator: Health assessment agency IDOM/ACSA
- Start date: 02, 2023
 - End date: 08, 2023
 - Position: Evaluator
 - Activities: Evaluation of patient centred care, management, healthcare quality of healthcare providers
 - Country: Spain

Education and training

1. Subject: Porto University
 - Start date: 10,2000
 - End date: 11,2006
 - Qualification: Graduate degree in Veterinary Medicine, DVM
 - Organisation: 1_year Junior researcher in electronic microscopy 3 months Internship in the USA_animal reproduction 6 years training; Genetics, Physiology, Biology & other
 - Country: Portugal
2. Subject: Lusófona University
 - Start date: 06,2011
 - End date: 05,2012
 - Qualification: Postgraduate studies in Soft Tissues Surgery
 - Organisation:
 - Country: Portugal
3. Subject: Évora University
 - Start date: 10,2011
 - End date: 04,2013
 - Qualification: PhD program in Veterinary Sciences _ Incomplete degree
 - Organisation: Research Projects on Leishmaniosis 2 papers published as co_author
 - Country: Portugal
4. Subject: EUPATI
 - Start date: 09,2015
 - End date: 10,2016
 - Qualification: EUPATI Fellow _ Expert Patient Training Course
 - Organisation: High skills development as patient expert in medicines R&D Capacitation to deliver advice to industry, regulators and ethics committees.
 - Country: Spain
5. Subject: EURORDIS Winter School
 - Start date: 03,2018
 - End date: 04,2018
 - Qualification: Patient expert
 - Organisation: Training on Scientific Innovation and Translational Research
 - Country: France
6. Subject: CComend / EATRIS training
 - Start date: 10,2017
 - End date: 11,2017
 - Qualification: Translation research qualification
 - Organisation: Intensive training in medicines R&D for PhD Students Build put knowledge in Translational research
 - Country: Germany
7. Subject: Évora University
 - Start date: 10,2021
 - End date: Present
 - Qualification: Doctorate program on Human Kinetics
 - Organisation: Biomechanics in achondroplasia and physical activity
 - Country: Portugal

Additional information

Publications

Jacinto M, Matos R, Alves I, Lemos C, Monteiro D, Morouço P, Antunes R. Physical Activity, Exercise, and Sports in

Individuals with Skeletal Dysplasia: What Is Known about Their Benefits? Sustainability. 2022; 14(8):4487. <https://doi.org/10.3390/su14084487>

Koromani F, Alonso N, Alves I, Brandi ML, Foessel I, Formosa MM, Morgenstern MF, Karasik D, Kolev M, Makitie O, Ntzani E, Pietsch BO, Ohlsson C, Rauner M, Soe K, Soldatovic I, Teti A, Valjevac A and Rivadeneira F (2021) The "Genomics of Musculo Skeletal Traits Translational Network": Origins, Rationale, Organization, and Prospects. *Front. Endocrinol.* 12:709815. doi: 10.3389/fendo.2021.709815 Muhammad Kassim Javaid, Mariana Mordenti, Manila Boarini et al. Patients' Priorities and Expectations on an EU Registry for Rare Bone and Mineral Conditions, 10 December 2020, PREPRINT (Version 1) available at Research Square [https://doi.org/10.21203/rs.3.rs_122665/v1]

Meeting report from the achondroplasia foramen magnum workshop, Austria, 22nd June 2019, *Bone journal*, July 2019 Alves I, Francisco T, Pinto H, Sousa S, Connor P, Amorim M, Ramos D, Azevedo S, Vandewalle B, Multi_criteria decision analysis of the value of Burosumab for the treatment of paediatric patients with X_Linked Hypophosphatemia in Portugal. *Bone Abstracts* (2019) 7 P144 | DOI: 10.1530/boneabs.7.P144

Pereira L, Martins L, Alves I, Semião_Santos S, Bento O. 2012. Allergologic evaluation of a dog population in a veterinary Immunology query: what correlates in a canine model. Proceedings of the XXXIII Annual Meeting of the Portuguese Society for Allergology. P21:20. *Revista Portuguesa de Imunoalergologia*. 2012

Alves I, Pereira MA, Veloso LB, Santos_Mateus D, Santos_Gomes G, Semião S, Martins L. Rastreio preliminar da suscetibilidade/resistência do Rafeiro do Alentejo à leishmaniose canina. Proceedings do VIII congresso do Hospital Veterinário Montenegro Endocrinologia; II Congresso de Enfermagem. Fevereiro de 2012

Meeting report from the achondroplasia foramen magnum workshop, Austria, 22nd June 2019, *Bone journal*, July 2019 Multi_criteria decision analysis of the value of Burosumab for the treatment of paediatric patients with X_Linked Hypophosphatemia in Portugal. June 2019

Projects

Research project as doctoral candidate on biomechanical, anthropometric, psychologic and nutritional characterization of adults with achondroplasia, Évora University

Memberships

- Portuguese Society of Human Genetics
- European Reference Network for rare bone conditions
- European Registry for rare bone and mineral conditions
- European Calcified Tissue Society
- EUPATI Portugal

Other Relevant Information

I am a patient representative