



## Curriculum Vitae

### Personal information **Ines Alves**

#### Work experience

---

##### Advocacy work

1. ANDO Portugal - Skeletal dysplasia National Association - Founder & President / May 2015 -ongoing
2. EUPATI Portugal - Founder & Vice-President / April 2017- ongoing

##### Expert Patient work

1. DLR Projekttrager – BMBF Funding initiatives on clinical trials – Germany

Invited evaluator to review research proposals calls on Clinical trials relevance for patient care / 2022 - ongoing

2. Andalusian independent assessment Agency (ACSA) - Spain

Invited evaluator for new applicants European Reference Networks / 2021, 2023, 2025

3. European Patients Academy for Therapeutic Innovation (EUPATI)

EUPATI Fundamentals trainer / Oct 2020- ongoing

4. HORIZON 2020 - IMI 2 Calls expert evaluator / Oct 2020- April 2021

5. Assisting lecturer at University of Évora - School of Health and Human Development – Department of Sports and Health

Lectures on Kinesiology, Human development and biomechanics / October 2023-ongoing

6. Global Registry for novel therapies in rare bone and endocrine conditions - Globe REG , Steering Committee member / Nov 2023 - ongoing

7. Innovative Health Initiative - IHI. Granted project evaluator / Feb- April 2025

8. Health parliament portugal Deputy / Dec 2019 -Nov 2020

10. European Registry for Rare bone disorders - EuRR-BONE, Co-chair of Patient Outcomes. Member of WG on achondroplasia / Nov 2019-ong

11. European Rare Bone Forum founder & steering group member. Founder and Steering group member / Nov 2019 - ongoing

12. Genomics of MusculoSkeletal traits Translational Network, COST Action Co-lead Translations outreach / Sep 2018 – April 2024

13. European Reference Network for rare bone Diseases - ERN BOND. Patient representative & Steering Committee member / April 2017- ong

14. Alpe foundation - Spain. Scientific adviser / May 2015 -Nov 2019

15. CVRM - Portugal - veterinary surgeon / Feb 2007- April 2014

#### Education and training

---

1. University of Évora

- Start date: 10,2021
- End date: ongoing
- Qualification: Doctoral program in Human Kinetics - Ph.D. candidate
- Organisation: Biomechanics in achondroplasia
- Country: Portugal

2. Comprehensive Health Research Centre (chrc)

PhD student & junior researcher

Sep 2022-ongoing

3. Lusófona University

- Start date: 06,2011
- End date: 05,2012
- Qualification: Postgraduate studies in Soft Tissues Surgery
- Organisation:
- Country: Portugal

4. 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
5. 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

#### Non-academic trainings

1. EURORDIS Winter School
  - Start date: 03,2018
  - End date: 04,2018
  - Qualification: Patient expert
  - Organisation: Training on Scientific Innovation and Translational Research
  - Country: France
2. 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
3. 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

## Additional information

### Publications

Portela Carvalho C, Martins A, Alves I, et al  
Familial cartilage-hair hypoplasia: prenatal ultrasound features and clinical outcomes in three siblings with identical RMRP variants. *BMJ Case Reports CP* 2026;19:e267490.

Alves, I., Fredwall, S.O., Hughes, M. et al. An overview of the International Consensus Statement on achondroplasia. *Orphanet Journal of Rare Diseases* 2025;20:100.

Portela Carvalho C, Alves I, Lemos C, Guedes-Martins L. Prenatal Diagnosis of Cartilage-Hair Hypoplasia: A Narrative Review. *Acta Medica Portuguesa*. <https://www.actamedicaportuguesa.com/revista/index.php/amp/article/view/23497>

Alves, I., Chandran, M., Albee, E., Davis, M., Hsiao, E. C., Petryk, A., ... Sleiman, M. (2025). Plain language summary of the outcomes of the 2025 International Consensus Statement on Achondroplasia. *Orphanet Journal of Rare Diseases*. <https://doi.org/10.1080/23995270.2025.2466921>

Hoover-Fong, J.E., Savarirayan, R., Alves, I. et al. Qualitative Research in Children and Parents of Children with Achondroplasia. *Journal of Child Neurology*. <https://doi.org/10.1007/s12325-025-03425-y>

Alves I, Westerheim I, Hsiao EC, et al. A systematic literature review of the impact and measurement of mobility impairment in achondroplasia. *Journal of Child Neurology*. <https://doi.org/10.1007/s12325-025-03425-y>

Alves, I., Castro, M.A., Tavares, S. et al. Adults with achondroplasia exhibit a high probability of specific micronutrient inadequacy. *Journal of Child Neurology*. <https://doi.org/10.1007/s12325-025-03425-y>

Beger C, Alves I, Carl-Innig P, Sessa M, Mohnike K, Cheung MS. Limb lengthening in individuals with achondroplasia: Analysis of the 2025 International Consensus Statement. *Journal of Child Neurology*. <https://doi.org/10.1007/s12325-025-03425-y>

Adedeji A, Witt S, Innig F, Alves I, Provasi C, Sessa M, Mohnike K and Quitmann J (2025) Coping and quality of life of parents of children with achondroplasia. *Journal of Child Neurology*. <https://doi.org/10.1007/s12325-025-03425-y>

Horn J, Leardini A, Benedetti MG, Hestnes TM, Mindler G, Wekre LL, Sangiorgi L, Alves I, Trisolino G. Fully instrumented gait analysis in achondroplasia. *Journal of Child Neurology*. <https://doi.org/10.1007/s12325-025-03425-y>

Alves, I., Chandran, M., Albee, E., Davis, M., Hsiao, E. C., Petryk, A., ... Sleiman, M. (2025). Plain language summary of the outcomes of the 2025 International Consensus Statement on Achondroplasia. *Orphanet Journal of Rare Diseases*. <https://doi.org/10.1080/23995270.2025.2466921>

Beger, C.; Alves, I.; Carl-Innig, P.; Sessa, M.; Mohnike, K.; Cheung, M.S. Limb lengthening in individuals with achondroplasia: Analysis of the 2025 International Consensus Statement. *Journal of Child Neurology*. <https://doi.org/10.1007/s12325-025-03425-y>

Alves, I., Koromani, F., Lemos, C. et al. Facilitators and constraints of physical activity in adults with achondroplasia: a scoping review. *Journal of Child Neurology*. <https://doi.org/10.1007/s12325-025-03425-y>

Alves, I.; Fernandes, O.; Castro, M.A.; Tavares, S. Physical Activity and Psychosocial Outcomes in Adults with Achondroplasia: A Scoping Review. *Journal of Child Neurology*. <https://doi.org/10.1007/s12325-025-03425-y>

Alves, I.; Castro, M.A.; Tavares, S.; Fernandes, O. Unveiling the Chaos in Postural Control in Adults with Achondroplasia. *Journal of Child Neurology*. <https://doi.org/10.1007/s12325-025-03425-y>

Alves, I., Castro, M.A., Tavares, S., Fernandes, O. (2023). Electromyography Analysis of Rectus Femoris and Biceps Femoris Muscles in Achondroplasia. *Portuguese Society of Biomechanics. CNB 2023. Lecture Notes in Bioengineering. Springer, Cham.* [https://doi.org/10.1007/978-3-031-23425-1\\_10](https://doi.org/10.1007/978-3-031-23425-1_10)

Fink S, Suppanz M, Oberzaucher J, Castro MA, Fernandes O, Alves I. Gait characterization in rare bone diseases in a real-world setting. *Journal of Child Neurology*. <https://doi.org/10.1007/s12325-025-03425-y>

Horn J, Leardini A, Benedetti MG, Hestnes T, Mindler G, Wekre L, Sangiorgi L, Alves I, Trisolino G, et al. Fully instrumented gait analysis in achondroplasia. *Journal of Child Neurology*. <https://doi.org/10.1007/s12325-025-03425-y>

Fully instrumented gait analysis in rare bone diseases – A scoping review of the literature (2025), *Gait & Posture*, 118, 168-177

Cheung MS, Alves I, Carl-Innig P, Eastwood D, Maghnie M, Offiah A, Paley D, Riganti S, Savarirayan R, Sessa M, Vogt B, Mohnke K. Achondroplasia, Salzburg, Austria 22nd June 2024. *Bone*. 2024 Oct 2; 190:117268. doi: 10.1016/j.bone.2024.117268. Epub ahead of print.

Fink S, Suppanz M, Castro MA, Fernandes O, Alves I. Perceived Mobility Challenges in Rare Bone Diseases: How Real-world Data Can Inform Us. *Frontiers in Endocrinology*. 2023 Jun 9; 13:117268. doi: 10.3389/fendo.2023.117268. Epub ahead of print.

Savarirayan, R., Ireland, P., Irving, M., Alves I et al. International Consensus Statement on the diagnosis, multidisciplinary management and care of achondroplasia. *Frontiers in Endocrinology*. 2023 Jun 9; 13:117268. doi: 10.3389/fendo.2023.117268. Epub ahead of print. <https://doi.org/10.1038/s41574-021-00595-x>

Chandran M, Alves I, Carpenter T, Davis M, Hsiao EC, Petryk A, Semler JO, Sleiman M. Improving care pathways for people living with achondroplasia. *Frontiers in Endocrinology*. 2023 Jun 9; 13:117268. doi: 10.3389/fendo.2023.117268. Epub ahead of print. PMID: 37294334; PMCID: PMC10382343.

Alanay, Y., Mohnike, K., Nilsson, O., Alves I et al. Real-world evidence in achondroplasia: considerations for a standardized data collection. *Frontiers in Endocrinology*. 2023 Jun 9; 13:117268. doi: 10.3389/fendo.2023.117268. Epub ahead of print.

Fredwall, S., Allum, Y., AlSayed, M., Alves, I et al. Optimising care and follow-up of adults with achondroplasia. *Orphanet J Rare Dis*. 2023 Jun 9; 18:117268. doi: 10.1038/s41574-021-00595-x. Epub ahead of print.

Jacinto, M.; Matos, R.; Alves, I.; Lemos, C.; Monteiro, D.; Morouço, P.; Antunes, R. Physical Activity, Exercise, and Sports in Individuals with Achondroplasia. *Frontiers in Endocrinology*. 2021 Aug 16; 12:709811. doi: 10.3389/fendo.2021.709811. Epub ahead of print. <https://doi.org/10.3390/su14084487>

Javaid, M.K., Mordenti, M., Boarini, M., Alves I et al. Patients' priorities and expectations on an EU registry for rare bone and muscle diseases. *Frontiers in Endocrinology*. 2023 Jun 9; 13:117268. doi: 10.3389/fendo.2023.117268. Epub ahead of print.

Koromani F, Alonso N, Alves I, Brandi ML, Foessel I, Formosa MM, Morgenstern MF, Karasik D, Kolev M, Makitie O, Ntzani E, Pieke-Barbier M, et al. "Translational Network": Origins, Rationale, Organization, and Prospects. *Front Endocrinol (Lausanne)*. 2021 Aug 16; 12:709811. doi: 10.3389/fendo.2021.709811. Epub ahead of print.

Cheung, M.S., Alves, I., Hagenäs, L., & Mohnke, K. (2019). Meeting report from the achondroplasia foramen magnum workshop. *Frontiers in Endocrinology*. 2019 Jul 23; 9:117268. doi: 10.3389/fendo.2019.0117268. Epub ahead of print.

## Projects

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

SPACES – Strengthening Primary and Community Health System - Innovative Telerehabilitation and Telemonitoring Approaches: Enhancing Accessibility and Patient-Centered Care (THCS funding - <https://www.thcspartnership.eu/>)

## Memberships

- Portuguese Society of Humans 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 and with more than 4 years in experience in assessing orphan medicinal products, with 5 rapporteurships and scientific advise. My background included veterinary medicine training with understanding in pharmacology, pharmacokinetics and also experienced in clinical trials design and patient involvement in research