

Partnership, Family Planning, and Pregnancy in Patients with Spinal Muscular Atrophy

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I. Background

- Although pregnancy for individuals with SMA involves medical risks, these are manageable with close medical supervision.
- However, patients and their families often face substantial information gaps and a high need for counseling. This is true for both women and men living with SMA, and the need persists before, during, and after pregnancy.
- Appropriate guidance and clear recommendations are crucial to prevent undesirable medical and psychosocial complications.
- To provide such guidance, it is essential to investigate attitudes towards partnership, family planning and pregnancy within a large and diverse group of individuals with SMA and their partners.

II. Objectives

- To examine pregnancies with SMA retrospectively, including the physical effects and medical complications.
- To explore partnership dynamics in couples where one partner is affected by SMA.
- To capture specific needs, as well as external and internal factors influencing family planning and the desire for children.
- To identify systemic barriers, such as inadequate assistive device provision or a lack of access to specialized counseling.
- To describe potential differences in the perspectives between patients and their partners concerning partnership, parenthood, desire for children and family planning.

III. Methods

- The **Pregnancy and Birth survey** is currently recruiting SMA patients in Austria, Canada, Czechia, New Zealand, Portugal, and the UK. Recruitment for this survey began in September 2024 and will **continue through Q4 2025**.
- Recruitment for the **Partnership and Family Planning** survey began in March 2025 and will **continue through Q4 2025**. Recruitment takes place in the same countries and includes both individuals with SMA and their partners.
- An international extension of the survey is currently in preparation, and **additional collaborators** are welcome.
- The **pregnancy and birth questionnaire** gathers data on SMA history, mobility, treatment, complications, delivery, postpartum recovery and newborn health.
- The **partnership and family planning questionnaire** assesses health status, living situation and five key domains: Attitudes toward pregnancy and the desire for children, barriers, partnership, attachment style and personality.
- Aside from a few disease-specific items, both versions of the partnership questionnaire are identical. This allows for dyadic analyses using the Actor-Partner Interdependence Model. [1]

IV. Selective preliminary descriptive results

Pregnancy and birth questionnaire			Partnership and family planning questionnaire		
Do you live in a committed relationship?			Do you wish to have children in the future?		
	Frequency	Percentage		Frequency	Percentage
Yes	132	58,7	Yes	10	32,3
No	93	41,3	No	13	41,9
n=225; Included answers from Austria (n=11), Canada (n=10), Germany (n=143), New Zealand (n=4), Poland (n=44) and UK (n=13)			I'm unsure	7	22,6
Do want a committed relationship?			Prefer not to say	1	3,2
	Frequency	Percentage	n=31; German SMA-Patients living in a committed relationship without children		
Yes	71	31,6			
No	22	9,8			
n=93; Patients not living in a committed relationship					

How many children have you given birth to?

	Frequency	Percentage
None	80	67,2
1	30	25,2
2	7	5,9
3	2	1,7

n=119; Included answers from female borne patients

The results demonstrate that partnership, family planning, and pregnancy are highly relevant topics for individuals with SMA. While most participants have not had children yet, those who are in a committed relationship actively consider future parenthood.

V. Outlook

- Based on the results of the surveys conducted among a large and heterogeneous cohort, we expect to gain a comprehensive understanding of the attitudes toward partnership, family planning, and the desire for children, from both a clinical-medical and a personal perspective. This will enable us to develop practical recommendations for healthcare professionals as well as affected couples.
- Additionally, we expect to identify a broader range of disease-specific barriers and challenges. This knowledge will help to create targeted support services and reduce obstacles.
- In relationships, there is mutual dependence: the feelings, perceptions, or behavior of one partner can influence those of the other. Dyadic analysis, using the Actor-Partner Interdependence Model (APIM), is crucial as it examines how the feelings, perceptions, and behaviors of one partner influence those of the other. [2]
- These insights are particularly valuable for clinical practice, as a successful pregnancy demonstrates medical progress in SMA treatment effectiveness and can strengthen confidence in one's own abilities.

VI. Recruitment

- Recruitment is currently ongoing** – we are including individuals with SMA and their partners.
- Your participation is highly valuable and will help us to gain a deeper understanding of partnership, family planning and pregnancy in SMA and to develop tailored recommendations for clinical care and support services.
- Participation is online, anonymous and takes 20–30 minutes per questionnaire.
- If you represent a **patient organization** or if you know **patients** who might be interested in participating, we would like to **invite you to support this project**. Please feel free to contact us directly; our contact details are provided below.



Scan me for more information or to participate!

[1] Kashy DA, Kenny DA (1999): The analysis of data from dyads and groups, H. T. Reis & C. M. Judd (Eds.), Handbook of research methods in social psychology, New York, Cambridge University Press; [2] Cook WL, Kenny DA (2005): The Actor–Partner Interdependence Model: A model of bidirectional effects in developmental studies, International Journal of Behavioural Development 2005, 29(2), 101-109.