

COMMENTARY

When a rare condition creates a scientific society: The history of the International Society for Placenta Accreta Spectrum (IS-PAS)

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Abstract

Almost 10 years ago, clinicians at multiple locations all over Europe observed an increased number of antenatally undiagnosed cases of placenta accreta spectrum (PAS) resulting in significant morbidity and the occasional maternal death. Even with an improvement in antenatal imaging, the management of severe PAS remains challenging. One solution to improve understanding in rare but potentially lethal conditions is international collaboration. Consequently, a European working group was formed, which over the next few years grew into an international society, the IS-PAS. The collective goals are to develop a large shared database of cases, generate high-quality research into all aspects of PAS, and improve education of both healthcare professionals and patients. The first results of this collaboration are presented within this supplement.

KEYWORDS

abnormally invasive placenta, accreta, cesarean hysterectomy, placenta accreta spectrum, pregnancy

Abbreviations: AIP, abnormally invasive placenta; EW-AIP, European Workshop on Abnormally Invasive Placenta; IS-PAS, International Society for Placenta Accreta Spectrum; PAS, placenta accreta spectrum.

*See Appendix for Members of the International Society for Placenta Accreta Spectrum (IS-PAS)

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1 | INTRODUCTION

This journey started in 2011, and almost simultaneously, at multiple locations all over Europe, with numerous obstetricians sharing a difficult experience. The stories vary but the underlying theme is remarkably similar: an unexpected abnormally invasive placenta (AIP) (usually a percreta) with no prenatal diagnosis followed by an unplanned cesarean hysterectomy, catastrophic postpartum hemorrhage, significant morbidity, and an occasional, tragic, maternal death. These cases profoundly affected the healthcare practitioners involved and all agreed something needed to be done.¹

On reviewing the scientific literature available, José Palacios Jaraquemada stood out.²⁻⁴ Contact was made with him by Reynir T. Geirsson, Jens Langhoff-Roos, and Frederic Chantraine at the European Congress on Gynecology and Obstetrics in Copenhagen, in September 2011, and a decision was taken to organize a workshop. In March 2012, the first European Workshop on "Abnormally Invasive Placenta" (EW-AIP) took place in Brussels. This knowledge exchange allowed the handful of participants to significantly improve their understanding of placenta accreta spectrum (PAS) and help to realize that international collaboration had to become a core philosophy if the management of this rare condition was to improve. An additional outcome from this collaboration was the publication in 2013 of a special issue on AIP in *Acta Obstetrica et Gynecologica Scandinavica* (AOGS).^{5,6} With no funding, the EW-AIP members met twice a year.

When the European collaboration started in 2011 the world was in turmoil regarding what constituted the complex condition of abnormally adherent and invasive placenta. Names rolled around the literature from "Morbidly Adherent Placenta" and "Placental Adhesive Disorders" to the particularly inventive, "Pernicious Placenta". There is no doubt that this added to the confusion surrounding the condition resulting in poor diagnostic criteria and highly variable prevalence figures. Addressing this scientific chaos was one of the main reasons the group was formed. After much discussion the group originally settled on abnormally invasive placenta, and so EW-AIP was born. We were aware that this only encompassed increta and percreta but given that we wanted to raise awareness regarding the end of the spectrum that posed the greatest threat to women, we were content to compromise with that. To facilitate worldwide collaboration and generate transparency (by publishing a ratified constitution), the European working group became an international society, the IS-AIP, in 2017.

However, swayed by FIGO (the International Federation for Gynecology and Obstetrics) guidelines (which many of our members were involved in) the term Placenta Accreta Spectrum has become rapidly adopted worldwide because it is the only term that covers the whole range of abnormally adherent and invasive placentation.⁷⁻¹² In light of this new nomenclature, our society once again reflected on our central ethos of international collaboration and considered changing the name of the society to the International Society for Placenta Accreta Spectrum (IS-PAS). We remain committed to working on the invasive end of the spectrum but hope that this move goes towards unifying clinicians and academics worldwide.

Key message

To improve the understanding and management of placenta accreta spectrum, the International Society for Placenta Accreta Spectrum (IS-PAS) was founded with the collective goals of a shared database, high-quality research, and improved education worldwide.

The foundation of IS-PAS is based on three collective goals: building a shared database of PAS cases between recognized referral centers; high-quality research into all aspects of the condition; and education for both healthcare providers and patients.

2 | THE DATABASE

Our first goal was to build a shared database of cases collected from selected referral centers that have expertise in the clinical management of PAS. With input from FETVIEW® an online database was developed allowing us to collect over 442 cases of PAS managed in referral centers initially from across Europe but now including the USA. This is a starting point. The database continues to evolve and as members from many more countries join the society, we hope that the information gathered will truly represent the global management of PAS, informing and educating as it grows.

3 | OTHER RESEARCH

The second collective goal of our collaboration was to deliver high-quality research into all aspects of PAS. We have sought to achieve this by first publishing studies aimed at standardizing ultrasound and MRI descriptors with a view to improving future imaging studies.^{13,14} Then, in 2019, we undertook the challenge of developing evidence-based guidelines for the intrapartum management of PAS. This involved 22 systematic reviews of the literature on a wide variety of relevant clinical questions.¹⁵ One of the further research goals is to investigate the pathology underlying PAS, including the building of a tissue and blood sample biobank.

4 | EDUCATION

From the beginning of the EW-AIP, education was a central pillar of our ethos. We have subsequently actively participated in many national and international scientific meetings and webinars to improve dissemination of the best possible diagnostic techniques and evidence-based management of PAS. We have recently reached out to patients by designing a patient information leaflet about cesarean delivery in association with PAS, which is available on the website and will soon be available in a variety of languages.

The last 9 years have been an incredible experience for all our members. We will see where the journey will us take in the next years, but for the time being the results of this collaboration are presented within this Supplement.

CONFLICTS OF INTEREST

None.

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APPENDIX

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