


# Playing sport as a central-line carrier: a survey to collect the European pediatric intestinal failure centers' view

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## Abstract

**Background:** The administration of home parenteral nutrition improves quality of life for patients with intestinal failure, thus fostering their will to actively participate to social activities. Nevertheless, sports participation can be risky for patients with a central venous catheter (CVC). Despite literature thoroughly proving the positive impact of sports on motor-psychosocial development, no consistent evidence assessing its role on central-line complications is available. This study aimed to report the European centers' approach to children with intestinal failure on home parenteral nutrition and interested in playing sports, further assessing complications and how to prevent them.

**Materials and Methods:** A questionnaire focusing on children with intestinal failure regarding physical activity was circulated to 20 centers. Questions assessed the centers' policy for CVC management, the sports-related recommendations for patients on home parenteral nutrition and complication rates.

**Results:** Sixteen (80%) centers filled in the questionnaire. Twelve centers reported not to have a standardized formal protocol for catheter care during sports. All centers encouraged patients to perform mild/moderate exercise, whereas high-contact sports were allowed by one center only. Specific dressings were suggested to protect the vascular access device, especially for water sports. Only one sports-related complication (rupture) was reported.

**Conclusion:** This survey emphasizes that sports should not be restricted in patients with intestinal failure and represents a blueprint for sports-related

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A complete list of the collaborating centers appears in the acknowledgments.

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recommendations for these patients. Prospective studies assessing complication rates are advisable to ensure an improved access to sports for these patients.

#### KEYWORDS

central-line catheter, home parenteral nutrition, intestinal failure, physical activity, short bowel syndrome, sports

## INTRODUCTION

Intestinal failure (IF) is a low prevalence condition (14.1–56 cases per million children)<sup>1–3</sup> characterized by impaired gut function, which hampers the absorption of macronutrients, water, and electrolytes. As a result, children with IF require long-term intravenous nutrition and hydration to maintain health and/or growth.<sup>4,5</sup>

The introduction of home parenteral nutrition (HPN) has led to improved health-related quality of life (HRQoL) and longer life expectancy for these patients, regardless of the underlying disease. Nonetheless, the need for a long-lasting vascular access introduces a risk factor for catheter-related bloodstream infections, thrombosis, and catheter malfunction.<sup>6,7</sup> These risks may result in increased morbidity, mortality and hospitalization.

Traditionally, performing physical activity with a central venous catheter (CVC) has been considered risky and therefore inadvisable, and so the need to assess complications related to participation in competitive sports was never considered by the medical community.

However, clear evidence shows that sports can positively influence children's motor development, bone density, self-esteem, and participation in daily life activities with peers.<sup>8</sup> This may be particularly relevant for IF patients on long-term HPN, up to 30% of whom may suffer from low bone density and poor bone mineralization. This is possibly due to several causes, including vitamin D malabsorption leading to osteomalacia, medication (such as steroids), and chronic intestinal inflammation,<sup>9–12</sup> which confer increased risk of fractures for these patients. As a result, healthcare professionals dealing with chronically ill children are progressively encouraging sports participation to maximize social interactions.<sup>13,14</sup> Analogously, recent guidelines on pediatric parenteral nutrition enunciate its optimal setting, so that patients can achieve a good HRQoL and participate in noncontact sports and swimming.<sup>15</sup> However, there is no literature on best practice or specific regulations for competitive and noncompetitive activity for CVC carriers.

In January 2022, an 11-year-old patient with IF receiving HPN requested a fitness certificate to play

competitive basketball. The absence of specific recommendations prompted the treating physician to discuss this specific request at European level via the European Commission–provided Clinical Patient Management System (CPMS; <https://cpms.ern-net.eu/login/?next=/insight/>). This web platform allows for general data protection regulation (GDPR)–compliant clinical case discussions among European experts. For this specific case, the panel of experts encouraged the release of the certificate on the basis of personal experience and prioritizing the patient's quality of life, while noting a wide variability in current clinical practices.

Therefore, the aim of this study was to collect the European Reference Network for rare Inherited and Congenital Anomalies (ERNICA) centers' approaches to children with IF and a central line who are interested in playing sports. The secondary objectives were to assess the extent of reported sports-related complications in this population and to summarize the protective measures that may help reduce complication rates.

## METHODS

A questionnaire focusing on patients on HPN regarding physical activity was prepared and sent as a Google Doc to the ERNICA members approved for the IF disease area (Appendix 1) in 11 countries: Austria, Czech Republic, Denmark, Finland, France, Germany, Italy, Spain, Sweden, the Netherlands, and the United Kingdom. ERNICA falls within the project of the European Reference Networks, and involves several expert centers on rare congenital anomalies. Criteria for membership are set by the European Commission and include the number of patients diagnosed, treated, and followed-up for the diseases covered by the network itself.<sup>16</sup>

All participating centers were asked about CVC-related sports recommendations.

The nonvalidated questionnaire was composed of 16 items, with 12 closed/multiple choice and four free-text questions. All IF centers were advised to fill out the questionnaire on behalf of the multidisciplinary team

and limit responses to one or two per center. Additionally, we specifically asked for these responses from members involved in the central-line management for patients with IF receiving HPN and coordinated responses from the experts within each center. The first part of the questionnaire focused on centers' practices for central-line management, with further questions referring to sport-related recommendations and risks, as well as complications. The responses were collected and analyzed using descriptive statistic. Treated patient volume was considered as a potential factor influencing each center's policy. A number of 15 patients receiving HPN was arbitrarily set as a cutoff to define larger and smaller volume centers.

Because the questionnaire was addressed to professionals and no patient data were retrieved, ethical permission was waived.

## RESULTS

A total of 16 of 20 ERNICA centers from 10 countries replied to the questionnaire (80%; Figure 1).

At the time of the survey, the number of CVC carriers receiving HPN varied between the centers. Specifically, 11 of 16 centers (69%) followed >15 patients, two centers (12.5%) between 10–15 patients, two centers (12.5%) between 5–10 patients, and one center (6.2%) <5 patients. When considering the type of CVC, all centers (100%) reported the use of centrally inserted central catheters (CICCs). Additionally, 8 of 16 centers (50%) also employed fully implantable catheters (Port-A-Cath), 5 centers (31%) employed peripherally inserted central catheters (PICC), and 1 center employed (6.2%) arterio-venous shunts.

### General sports-related indications for central-line care

Most of the centers (75%) reported not having a standardized formal protocol for physical activity-related CVC care. Of the four centers with a defined protocol, three centers recommended the use of special dressing for water sports and its replacement after direct water contact. Additionally, two centers discouraged the practice of high-contact sports (eg, martial arts, boxing).

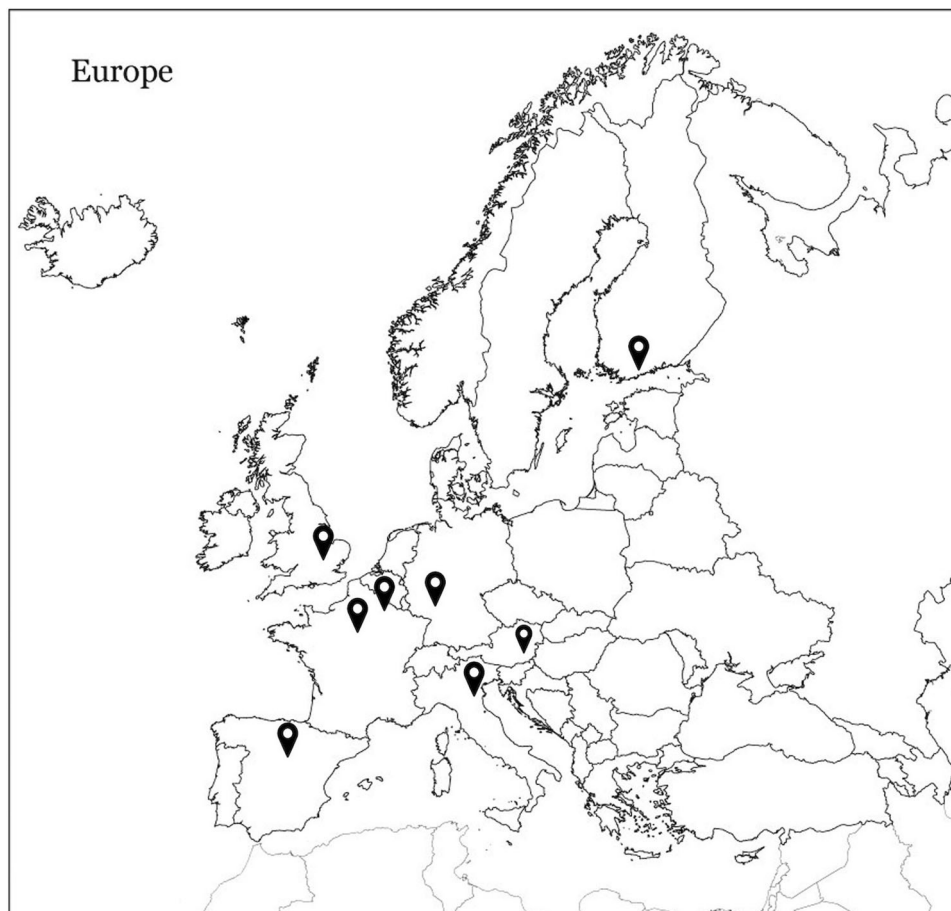


FIGURE 1 Map of the centers involved in the survey.

When asked about the type of physical activity healthcare professionals encouraged patients to perform (Table 1), all centers (100%) agreed on mild/moderate exercise, such as recreational activities with peers. Conversely, competitive and noncompetitive high-contact sports, such as martial arts or boxing, were reported as allowed by one center only (6.2%). Details can be found in Figure 2.

Fifteen centers (94%) stated they provided special recommendations for patients playing sports: use of adequate dressing for physical activity (nine centers; 60%), avoidance of high-contact sports (two centers; 13.3%), and regular cardiac assessments (one center; 6.7%). Among the

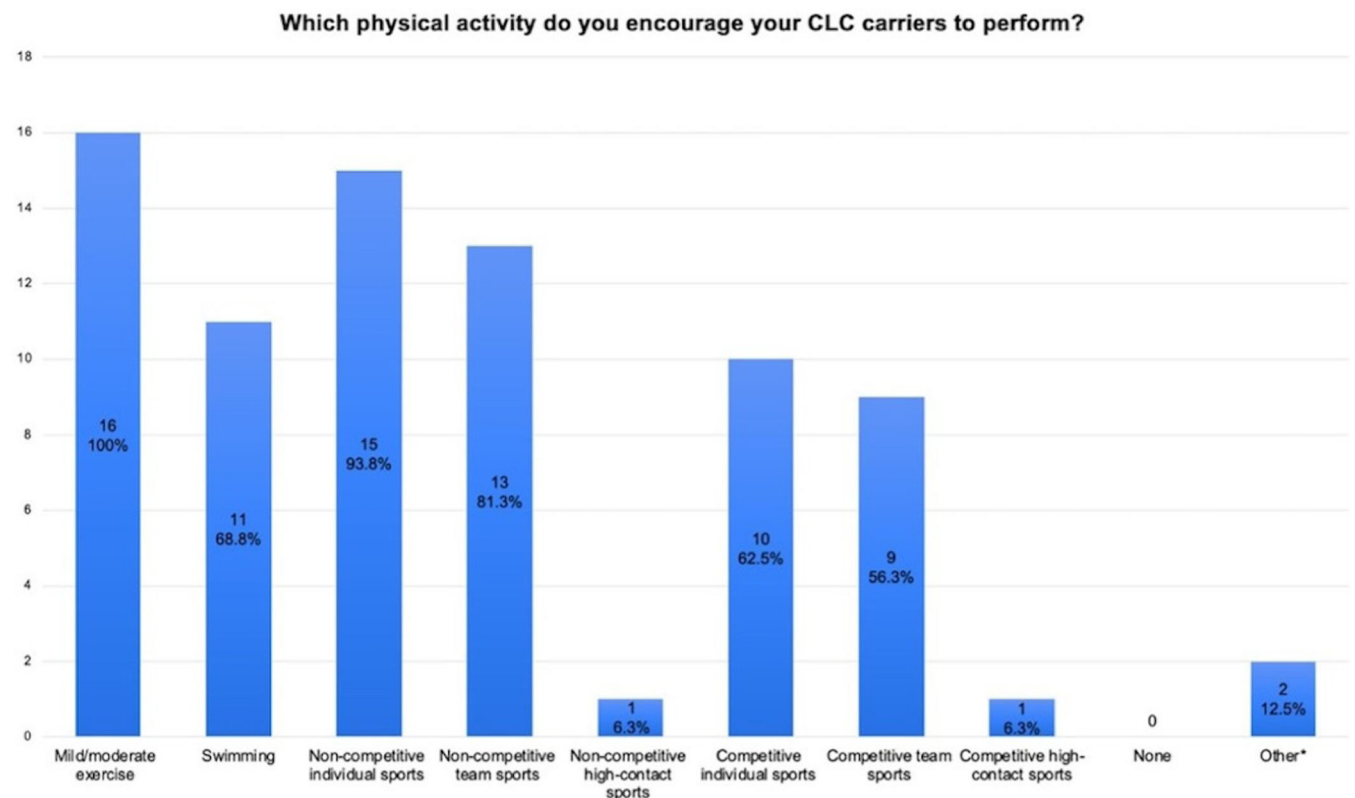
two centers discouraging high-contact activity, one center only restricted the indication to patients receiving heparin treatment.

### Specific sports-related indications for central-line care

The type of CVC in place led to different sports recommendations for seven centers (44%), with additional care being advised for CICC and PICC compared with fully implantable devices (eg, avoid water sports or use special dressings). Patient age and underlying disease did not

**TABLE 1** Definitions of different levels of physical activity.

Type of physical activity	Definition
Recreational activity	Nonstructured training sessions (eg, outdoor games), mild/moderate exercise
Noncompetitive sport	Individual or team structured training sessions, aiming at leisure but not at competition
Competitive sport	Individual or team structured training sessions aiming at competition and focused on athletic success
High-contact sport	Discipline that requires or place an emphasis on physical contact between players (eg, boxing, martial arts, rugby and similar, wrestling)



**FIGURE 2** Overview of the physical activity clinicians encourage CVC carriers to perform. The “other” category includes individual considerations based on age ( $n = 1$ ) and/or catheter type ( $n = 1$ ). CVC, central venous catheter.

imply a difference in recommendations for 14 (88%) and 13 (81%) centers, respectively.

Referring to sports-related CVC complications, only one center (6.2%) reported a rupture occurring during noncompetitive activity. Patency of blood vessels was not considered a determining factor to allow physical activity in 10 of 16 (62.5%) centers; among these, one center (6.2%) limited sports mainly on the basis of the CVC insertion site (eg, sports not recommended for femoral CVC) or in case of ongoing heparin treatment. Six centers (37.5%) adjusted sports recommendations according to the vascular patrimony: vessel patency for eventual CVC repositioning. Overall, centers treating >15 patients with HPN showed a tendency to consider the vessel situation when providing sports recommendations compared with those with <15 patients. No other differences in practice were found between smaller and larger volume centers.

## DISCUSSION

The CPMS case discussion regarding the release of a patient's fitness certificate highlighted a center-specific approach to sports in CVC carriers. Consequently, this survey was developed to gather the ERNICA centers' experience.

Over the past decades, improvements in medical care and the refinement of parenteral nutrition have resulted in survival rates of up to 90% for patients with IF.<sup>2,17</sup> Alongside this, the introduction of HPN enabled IF patients to achieve a quality of life comparable to that of healthy peers.<sup>18–20</sup> As a consequence, their desire to participate in sports, which is beneficial for their social and behavioral development, is progressively increasing, emphasizing the need for updated best-practice guidelines on CVC management and any disease-specific restrictions.

Current literature on sports-related CVC complications is scarce and lacks consistent evidence. The few existing studies on central-line management primarily focus on patients with cancer and/or concentrate on dressing management in relation to swimming and/or water sports.<sup>21–23</sup>

However, patients with cancer represent a considerably high-risk population for CVC-related complications, such as central-line-associated bloodstream infections, often impacted by to immunosuppression, and venous thromboembolism.<sup>24–28</sup> Moreover, it is worth mentioning that cancer patients (in contrast to most patients with IF) typically maintain the central line for shorter periods, and their physical fitness during that period can be reduced because of the underlying disease process and the ongoing treatment.<sup>29</sup> Despite these considerations, physical activity is usually not restricted for cancer patients because of its positive impact on HRQoL during and after cancer treatment.<sup>29</sup>

Intestinal failure may represent a lifelong condition characterized by extended periods of clinical stability, during which patients must manage a long-term CVC. As a result, CVCs are regarded as life-saving devices, prompting patients and parents to take meticulous care in maintaining and safeguarding them. These factors, along with a potentially lower risk of disease-related thromboembolic and infectious complications compared with cancer, contribute to a nearly normal HRQoL for patients with IF. In this regard, similar to other patients with a long-term condition, physical activity would not only enhance their psychosocial well-being but also positively influence the development of their motor skills.<sup>30</sup> Furthermore, physical activity may help preserve bone density and mitigate bone loss.<sup>31,32</sup> Therefore, children with long-term conditions should not be disadvantaged yet may be encouraged and supported to engage in regular exercise and athletic activity.

Results from this survey support this approach, with all participating centers promoting physical activity among patients with IF. One center specifically noted the positive impact of sports on patients' quality of life, encouraging physical activity regardless of clinical status. Corroborating furthermore, only one sports-related CVC rupture necessitating a new central-line placement was reported, potentially suggesting that sports pose a low risk for CVC complications in this patient group. This study, together with recent literature,<sup>15,21,30</sup> may encourage clinicians to advocate for regular physical activity for CVC carriers with IF, with consideration for the need for specific precautions and regular clinical assessments.

Reported preventive measures to avoid CVC damage consisted of appropriate dressing or bandage to prevent friction and traction, transparent film allowing proper exit site inspection, and dressing change after every training session or in case of dressing soiling or rupture. Additional suggestions for swimming and water sports included using waterproof films and custom technical equipment. One center specified the use of transparent moisture-responsive catheter dressings, covered by a large wound dressing (eg, absorbent foam dressing). Furthermore, two centers mentioned the application of hydrocolloid dressings and alcohol-containing caps for disinfection/protection. Such dressings and devices represent general indications that should be adapted based on the materials available at each center. Regarding swimming attire, one center advised girls to use a swimming suit (not a bikini) to prevent line from stretching or getting stuck. Similarly, boys were advised to use a "swimming shirt" or extra dressing. Dressing changes were recommended immediately after training or after direct water contact, with a higher frequency compared with nonwater sports. A summary of the most commonly reported preventive measures can be found in Table 2.

**TABLE 2** Summary of the participating centers' dressing suggestions for water and nonwater sports.

Water sports	Nonwater sports	General
Use of transparent films covered by large waterproof dressings (eg, absorbent foam dressing); girls use swimming suit, not bikini; boys use "swimming shirt" or extra dressing	Use of large dressing and/or bandage; use of transparent film	Use of disinfecting cap locks (eg, disinfecting caps for needleless connectors); frequent dressing change

The above mentioned measures are particularly important for CICC and PCCC because fully implantable catheters usually have a lower risk for sports-related complications (eg, dislodgment, direct water contact). The CVC insertion site should also be considered when tailoring recommendations and advice on catheter dressings (eg, subcutaneous femoral catheters are more likely to be pulled and have higher risk of infections and thrombosis).<sup>21,33</sup> In this regard, further studies may clarify the safety of sports activities for CVC carriers and provide additional insights into the most effective preventive measures and dressings.

Recent guidelines on HPN recommend monitoring patients with IF on an annual or biannual basis. Beside physical examination and blood tests, assessment of liver disease via ultrasound, bone density, body composition, and chest x-ray to verify the position of the central line can be considered. However, no vascular assessment is foreseen in the advised follow-up program.<sup>15</sup> Nevertheless, as indicated by responses from some large-volume centers, understanding the patient's vascular situation could help tailor sports recommendations when needed. Several methods exist to investigate vessel patency, with point-of-care ultrasound being the most cost-effective and accessible, especially in an outpatient setting.<sup>34</sup> However, its role in decision-making for sports accessibility is complex. When considering competitive sports, a fitness certificate may be required, depending on national regulations. Sports physicians are usually responsible for issuing these certificates and can rely on standard regulations for both patients with and without disabilities. According to the International Paralympic Committee, disabled patients should undergo general and disease-specific evaluations, such as initial electroencephalogram and regular neurological assessments for neurologically impaired patients.<sup>35–38</sup> Nonetheless, patients with IF do not fit into the categories for paralympic athletes, although they do require additional physical assessments compared with healthy peers. As a result, nationally appointed healthcare professionals for the provision of fitness certificates often make decisions without available evidence or dedicated IF-expert physician. A standardized pathway for evaluating patients with IF, as well as the nomination of reference healthcare professionals, is essential to ensure access to competitive physical activity for these patients. Although further evidence would

be needed to best guide patients with IF towards sports, the development of clinical trials on this topic is challenging. Hence, experience-based practices should be considered. With this in mind, the results of the current survey suggest relevant considerations for defining CVC sports-related recommendations in patients with IF. The summary of the results and take home messages are as follows:

- CVC carriers with IF should be encouraged to play sport;
- tailored recommendations should always consider sport's impact on HRQoL;
- appropriate dressing should be recommended during physical activity, as well as dressing change after swimming; and
- competitive sport should not be restricted a priori.

## CONCLUSION

Based on the responses from ERNICA IF centers, participation in sports is not currently restricted for patients with IF with a CVC. Children and adolescents are instead encouraged to engage in physical activities to improve social and physical development. As suggested by the participating centers, appropriate dressing and technical equipment may further minimize the risks. Lastly, an individual approach based on the most recent clinical evaluation should guide decision-making and help tailor criteria for access to competitive activity.

Prospective collection of sports-related data in CVC carriers might play a key role in the assessment of the actual complication rates, as well as in the standardization of the evaluation process for competitive activity. This may result in an eased access to physical activity, further improving IF patients' HRQoL.

## COLLABORATING HEALTHCARE PROFESSIONALS

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### AUTHOR CONTRIBUTIONS

Rebecca Pulvirenti and Miriam Duci equally contributed to the conception and design of the research; to the acquisition, analysis and interpretation of the data; and the writing of the manuscript. Francesco Fascetti-Leon contributed to the conception and design of the research; to the analysis and the acquisition of the data; to the interpretation of the data; and to the critical revision of the manuscript. Cecile Lambe, Annika Mutanen, Henrik Arnell and Merit M. Tabbers contributed to the interpretation of the data and the critical revision of the manuscript.

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### CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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