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## **Response to Leboyer et al., 2026 - refers to: Advocacy by nonprofit scientific institutions needs to be evidence-based: a case study**

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## Response to Leboyer et al., 2026

First, we thank Leboyer et al. for allowing us to clarify several points regarding our paper. Second, we note that the main messages of our study (Gonon et al., 2025) are not questioned. In particular, Leboyer et al. do not dispute our critical analysis of the claim, based on the study by Henry et al. (2017), that a first assessment in expert centers led to a 55 % reduction in hospitalization days. Likewise, the evidence we present that this claim has been repetitively put forward in advocacy activities geared toward politicians (Gonon et al., 2025), have not been challenged.

We acknowledge that our characterization of the FondaMental Foundation as a semi-public structure may not be the formal legal terminology. However, although governed by private law, the foundation coordinates expert centers that were created by the French Ministry of Research in 2007 and are funded by the French Ministry of Health. It is important to ensure that readers understand these political and financial ties, which could otherwise be easily overlooked. We also noted that the foundation engages at times with a range of stakeholders, including pharmaceutical companies. Other French foundations, such as the Denicker Foundation, which operates within a scope very similar to that of the FondaMental Foundation, may likewise have an interest in engaging with both public and private actors. We regret if the term “competes” was perceived negatively; instead, we could have said “co-exists with similar aims and partly relying on overlapping sources of funding and academics to collaborate with”.

Regarding the partnership with Korian (Clariane group), it was never our claim that patients' clinical data were not anonymized. We only mentioned what was written in the press release jointly published by the foundation and by Korian on May 17th, 2023: “clinical and biological databases (FACE and BIO-FACE) will be shared with Korian's research teams, to guide diagnostic and therapeutic strategies” (Desplats, 2023).

Leboyer et al. deplored our focus on Henry's study (Henry et al., 2017), and, specifically, on its claim about a 50 % hospitalization reduction. In our study we justified this focus with four reasons (Gonon et al., 2025). In particular, due to hospitalization costs, this claim is very appealing for politicians. Moreover, this claim played a central role in the advocacy activities of the foundation. Indeed, we have systematically collected publicly accessible documents that reported interactions between the FF and parliamentary members, and that substantiated the principal request of the foundation: integrating Expert Centers in the healthcare system. In the text of these documents, the only quantitative index that was cited to demonstrate the therapeutic effectiveness of these centers was the 50 % reduction in hospitalizations days (our Table 4). Finally, we reported that this appealing claim was incorporated into a French parliamentary bill (Gonon et al., 2025). We acknowledge that Henry's study explored multiple outcomes (Henry

et al., 2017). However, as for hospitalization reduction, the causal interpretation of the other data is limited due to the lack of a control group and to likely regression to the mean.

Leboyer et al. underlined that “several additional studies” documented the therapeutic effects of Expert Centers. They gave three examples. However, all three studies also lacked an adequate control group to support a claim of effectiveness for expert centers. Moreover, Leboyer et al. pointed out a narrative review summarizing “key finding” from FACE-BD cohorts (Leboyer et al., 2022). This narrative review pointed out a 50 % reduction in hospitalization days after a first assessment in expert centers and this claim was only supported by citing Henry's study (Henry et al., 2017).

In conclusion, we maintain that our analysis describes a case of advocacy by a nonprofit scientific institution that was not evidence-based. We note that Leboyer et al. did not comment on those advocacy activities. In our view, it would have been more informative for the foundation to clarify its perspective on the extent to which the evidence it generates should influence health policy decision-making; the level and types of evidence considered appropriate for policymaking, particularly when supporting such extraordinary claims; how conflicts of interest are managed in this context; and the appropriateness of advocacy (or lobbying) activities within the policy process, especially when astonishing claims find their way into parliamentary legislation.

### CRedit authorship contribution statement

**François Gonon:** Writing – original draft, Writing – review & editing. **Henri Gouraud:** Writing – review & editing. **André Gillibert:** Writing – review & editing. **Bruno Falissard:** Writing – review & editing. **Lisa Cosgrove:** Writing – review & editing. **Kasper P. Kepp:** Writing – review & editing. **Ioana A. Cristea:** Writing – review & editing. **Florian Naudet:** Writing – original draft, Writing – review & editing.

### Declaration of competing interest

- François Gonon: None
- Henri Gouraud: None
- André Gillibert: None
- Bruno Falissard: None
- Lisa Cosgrove: She is part of the Lown List of Industry-Independent Health Experts.
- Ioana Cristea: She is part of the Lown List of Industry-Independent Health Experts.
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