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Dear families affected by Phelan-McDermid syndrome (PMS),

It has come to the attention of the PMS Medical Advisory Committee that some individuals with PMS experience significant adverse reaction to anesthesia in the context of medical procedures (e.g., dental; imaging). For this reason, we wanted to provide the following guidance that we hope will inform discussions of risks and benefits:

- Adverse effects from anesthesia appear to be quite rare;
- Most people with PMS have had anesthesia without any complications;
- Propofol is a relatively standard anesthetic and generally well tolerated;
- Benzodiazepines (e.g., lorazepam; midazolam) are also commonly used during anesthesia and are well tolerated; there are rare cases of adverse reactions with benzodiazepines (e.g., agitation) but they diminish quickly;
- Neuroleptics (i.e., antipsychotics) are sometimes used in general anesthesia and should be avoided.

Please feel free to share this letter with your providers.

Sincerely,

A handwritten signature in black ink that reads "A. Kolevzon, MD".

Alex Kolevzon, MD
Chair, PMS Medical Advisory Committee

Clinical Director, Seaver Autism Center for Research and Treatment
Icahn School of Medicine at Mount Sinai