

Robert Kolker's compassionate reporting on one family's discovery of their inheritance of a genetic variant that can lead to frontotemporal dementia captures the cruel nature of this disease, and the resilience of those affected. The family's painful diagnostic journey, and individual members' reckoning with what to learn about their own genetic fates, underscore that FTD requires a compassionate response from medical professionals, employers, insurers and policymakers. The majority of FTD cases are not inherited, but research into genetic FTD is bringing new hope for disease-modifying treatments for all. Biopharma investment is likely to continue to grow as more families get access to diagnoses, and the F.D.A.'s evolving openness to adaptive trial designs for rare diseases like FTD can also speed the path to the first approved treatments. Families need our help today. And they are ready to take action. A community that has been through so much can offer support and understanding to fellow travelers on a heartbreaking journey.

*Susan L-J Dickinson, chief executive officer,
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