S.L. has Rett syndrome, which is caused by mutations in the MECP2 gene on the X chromosome. (For further information on Rett syndrome, see the International Rett Syndrome Association website, www.rettysyndrome.org, and the Rett Syndrome Research Foundation website, www.rsrf.org.) Early development is normal in children with Rett syndrome, but there is then loss of purposeful limb use, and the development of distinctive hand movements, seizures, and mental retardation; they can also develop scoliosis and other anatomical deformities. S.L.’s first percutaneous endoscopic gastrostomy (PEG) was placed in April 2001, inserted medially because of her physical deformities, and she made a good recovery. A replacement balloon PEG was inserted in April 2005 to avoid the need for further endoscopies. S.L. started having severe diarrhea. Her full blood count, renal, liver, and thyroid function, clotting screen, and vitamin B12 and folate levels were all normal. Stool and blood cultures were negative. S.L.’s feeds were changed but this did not help. Her PEG was re-inserted in September 2005, when placement in the transverse colon was ruled out by applying suction on the needle on withdrawal from the stomach. S.L. remained stable after this procedure.

We believe the first PEG tube had gone through the transverse colon into the stomach, and that the replacement tube had ended up in the transverse colon. The patient survived by retrograde flow of the feed from the transverse colon, through the fistula, into the stomach. This case shows that even if a PEG tube is inserted endoscopically, there may be unexpected changes in the anatomy. Careful consideration should be given to determining the position of the PEG tube, so assuring the safety of surrounding organs.

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