

Figure 10: Scenarios if one parent passes before the other

is there a wound
in hearing
my father leave
for work, late at night
or early in the morning,
then dropping to my knees
eyes shut, to implore:

“My Lord and Savior
Jesus Christ, please
bring my parents home
to safety, please don’t let
them pass away, please may
no harm come to them, please
grant their long and healthy
life, in Your holy name
I pray, amen.”

with clenched hands
until the cranking of the garage
and the squeak of the front
door confirm that my prayers
had been answered

is this a wound that requires
treatment, or do I just call it
— thanatophobia

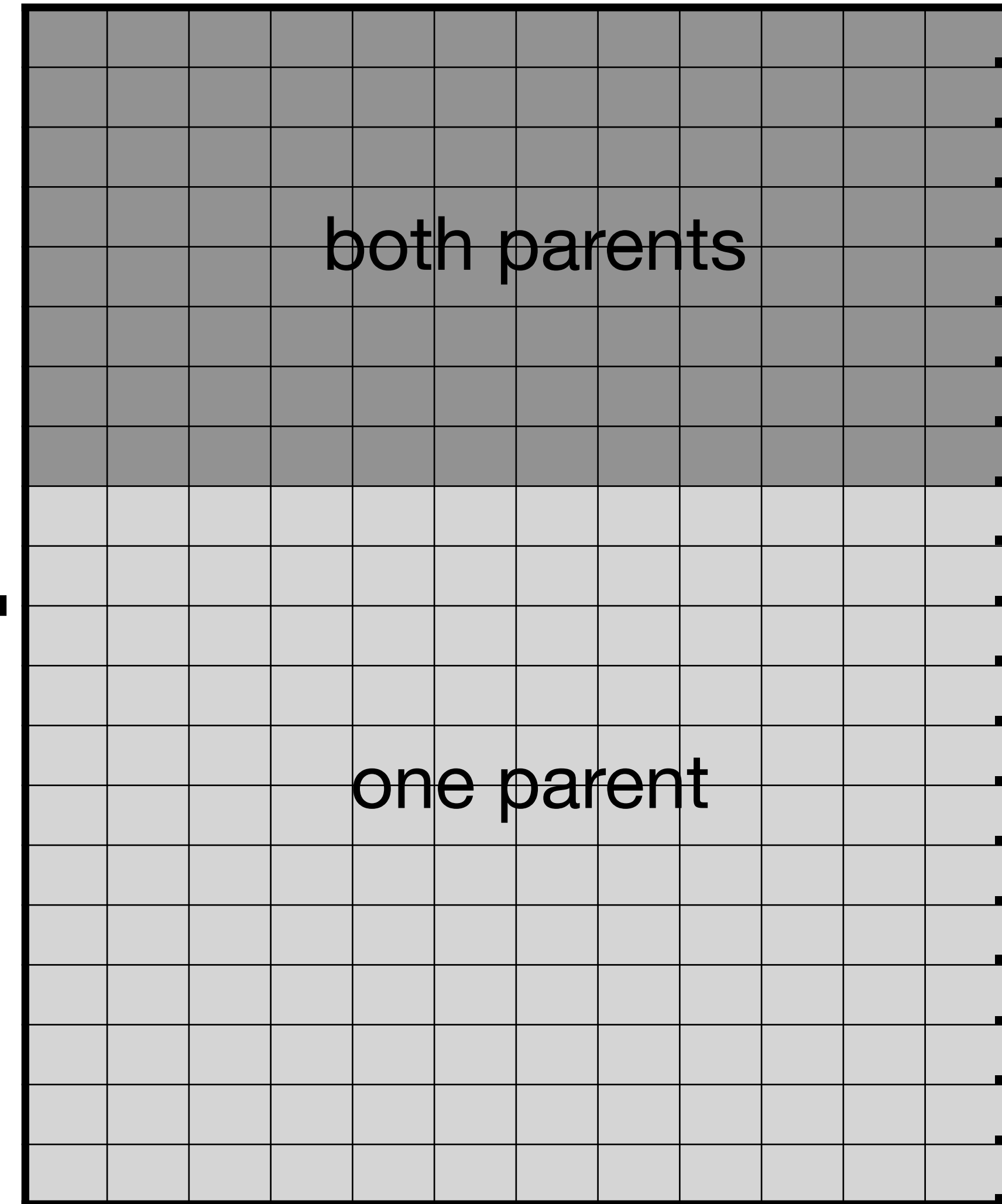
NOTES - 8.15.2023

Zoom call with Dr. [REDACTED], Mayo Clinic

Topic: New drug: *Patisiran* (Onpattro)

- Remember *tafamidis* is a drug that stabilizes, while the other ones are silencers that prevent most of protein from being formed.
- But neither drug takes amyloids directly out of the heart. If you actively take them out of the heart, what’s going to be left is basically just swiss cheese.
- So far we haven’t found a drug that’s been proven to be effective. We know that the drugs available so far, for the vast majority of people, the disease tends to progress. People tend to still progress, though at a much slower rate.
- Before, the average life expectancy was three and a half years for people with this condition. Now we’re seeing people doing better for a longer time. Most of the time the drugs don’t make someone feel better; they keep you from being worse.
- There is a new drug coming soon, that could be approved as early as this fall: *patisiran* (sold under the name Onpattro).

1x per year, for 20* years:



*20 years is a highly arbitrary duration; actual time may end up being a bit more, and most likely drastically less, especially when considering that a) actual progress won’t occur at a consistent rate, b) one of them has a rare condition which medication may or may not reverse and at best can only slow, c) things like car accidents, heart attacks, strokes, can happen all the time, and d) one of them doesn’t like to eat vegetables.