



[AmyloidosisSupp](#): Optimal condition for NEOD001 is in conjunction with chemo."Shut off the factory and promote clearance of what has accumulated." [#ASGDetroit](#)
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[AmyloidosisSupp](#): [@MorieGertz](#) On patients reading med lit--Hard to place info in context, what's an irrelevant observation, what's a breakthrough. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Anticipate starting phase 2/3 study in 4th quarter for NEOD001. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Interim analysis of Phase 1 data on NEOD001 to be presented Tuesday, April 29 at International Symposium on Amyloidosis. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Understand what you want to achieve from participating in clinical trial. Talk to primary physician, investigator, caregiver. [#ASGDetroit](#)
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[AmyloidosisSupp](#): NEOD001 prevents toxicity of soluble proteins and promotes clearance of aggregated insoluble proteins. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Proposed mechanism of action for NEOD001--Neutralize or facilitate clearance of amyloid protein. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Current research on AL [#amyloidosis](#) is focused on shutting down factory in plasma cells. NEOD001 targets aggregated light chains [#ASGDetroit](#)
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[AmyloidosisSupp](#): NEOD001 allows light chains to function normally. ID part of amino acid inaccessible when folded properly. Targets only misfolded. [#ASGDetroit](#)
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[AmyloidosisSupp](#): They study misfolded proteins across different diseases. Working on NEOD001 for 6-8 years. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Who is [@ProthenaCorp](#) ? We treat proteins in novel ways to resolve unmet clinical needs in patients. Focus on misfolded proteins. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Elevated heart rate is common after stem cell transplant. May last 6 months. [#ASGDetroit](#)
about 6 hours ago



[AmyloidosisSupp](#): [@MorieGertz](#) "Talking about how long someone has to live is just dumb. Statistics are averages, accurate but they are averages." [#ASGDetroit](#)
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[AmyloidosisSupp](#): Maximum light chain reduction can be seen 30 days post stem cell transplant. [#ASGDetroit](#)
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[AmyloidosisSupp](#): [@MorieGertz](#) "We do good work, we just don't warranty it." [#ASGDetroit](#)
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[AmyloidosisSupp](#): Nails can spoon, ridge, bend due to protein loss because nails are built from protein. Heal kidneys, nail usually come back. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Nervous system recovery from [#amyloidosis](#) is not very good. True damage from [#amyloidosis](#) not from drugs. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Liver can also recover. Kidney and liver are very healable organs. Just takes time after response up to 3 years. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Kidneys with this disease after stem cell transplant can heal completely. [#ASGDetroit](#)
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[AmyloidosisSupp](#): If organs not healed, light chains still elevated or disease returned, consider clinical trial as next step. [#ASGDetroit](#)
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[AmyloidosisSupp](#): If organs healed and light chains normal, clinical trials do not apply. [#ASGDetroit](#)
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[AmyloidosisSupp](#): This is different than some centers that do tandem, back to back, transplants. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Stem cell transplant can be repeated if long first response (5+ years) and still deemed safe. [#ASGDetroit](#)
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[AmyloidosisSupp](#): 47 yo with 13 year response to stem cell transplant, made sense to do additional transplant. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Mayo experience is that you can only poison garden twice, ie 2 stem cell transplants. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Takes weeks for seed to germinate and rebuild garden, ie rebuild ability to create blood. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Increase weed killer from 2 tsp to 2 cups to kill entire garden, then put seeds (stem cells) back to grow garden from scratch. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Give fertilizer shots to stimulate production and puts seeds from garden out in bloodstream. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Bone marrow is garden for blood component production. Chemo is weed killer but can cause too much damage. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Sometimes chemo can't be high enough to effect plasma cells without damaging other cells. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Drugs to kill plasma cells (chemo) can also cause damage to nerve cells causing tingling, numbness, pain. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Plasma cells are the source of the amyloidgenic proteins. All we have is blunt instruments--kill plasma cells with chemo. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Chronic heart and kidney disease can cause some anemia but not to the levels seen in multiple myeloma. [#ASGDetroit](#)
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[AmyloidosisSupp](#): 1 person in 50 has multiple myeloma and [#amyloidosis](#). [#ASGDetroit](#)
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[AmyloidosisSupp](#): Avg amyloid patient has 5% plasma cells in bone marrow. Avg adult has 1%. [#amyloidosis](#) pts plasma cells won't incr. over time. [#ASGDetroit](#) about 8 hours ago



[AmyloidosisSupp](#): In [#amyloidosis](#), screws and nuts become 3/4 in, wrench is still 1/2 in. Body can't disassemble them. [#ASGDetroit](#) about 8 hours ago



[AmyloidosisSupp](#): Light chain proteins and immunoglobulins only made by plasma cells and only in bone marrow. [#ASGDetroit](#) about 8 hours ago



[AmyloidosisSupp](#): Most common protein that can't be disassembled is immunoglobulin, antibody made in response to infections, cuts, vaccinations. [#ASGDetroit](#) about 8 hours ago



[AmyloidosisSupp](#): Body will make stuff that isn't fully biodegradable. Assembly kit--1/2 in screw, 1/2 in nut, 1/2 in wrench, screwdriver. [#ASGDetroit](#) about 8 hours ago



[AmyloidosisSupp](#): After 4 mos, red blood cell goes to recycling center. Everything is reused, proteins are efficiently used. [#ASGDetroit](#) about 8 hours ago



[AmyloidosisSupp](#): Everything body produces is supposed to be biodegradable and recyclable. Oldest red blood cell in body is 4 mos old. [#ASGDetroit](#) about 8 hours ago



[AmyloidosisSupp](#): Abnormalities of liver involvement do not show up on CAT scans, MRI. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Very subtle symptoms of liver inv. in [#amyloidosis](#) patients. Develop distaste for protein, eat high starch, high weight loss. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Pacemakers are often used to help regulate electrical system in cardiac [#amyloidosis](#) patients to help regulate heart beat. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Electrical system in heart is embedded in muscle and amyloids are in muscle interfering with the electrical system. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Pleural effusion can develop from kidney involvement due to lack of protein in blood. Causes fluid to build up around lungs. [#ASGDetroit](#)
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[AmyloidosisSupp](#): True lung involvement in systemic [#amyloidosis](#) is quite rare. Fluid issues do not indicate [#amyloidosis](#) in lung. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Body is a poor judge of identifying fluid in lungs or around lungs. [#amyloidosis](#) causes fluid around lung triggering dry cough. [#ASGDetroit](#)
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[AmyloidosisSupp](#): If doctors wait for macroglossia, will miss 5 out of 6 patients. Only affects 15% of patients. [#ASGDetroit](#)
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[AmyloidosisSupp](#): 2 causes of thickened heart wall--high blood pressure & [#amyloidosis](#). Physicians will go with likely answer high blood pressure. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Heart fibers work together to pump blood. Amyloid deposits between fibers causing heart thickening. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Heart works so much harder at rest creating hyper-metabolism leading to weight loss--not 5 pounds in 6 months but 30. [#ASGDetroit](#)
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[AmyloidosisSupp](#): [#amyloidosis](#) heart rate elevated at rest. Gets message to pump more but it can't causing muscle fatigue and out of breath. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Under activity, muscles send message "Send more blood" causing heart to pump better 2 ozs goes to 2.5 ozs, heart rate goes up. [#ASGDetroit](#)
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[AmyloidosisSupp](#): [#amyloidosis](#) affected heart will move 80 ozs of blood per minute, enough for rest but not for activity. [#ASGDetroit](#)
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[AmyloidosisSupp](#): "Why am I so weak with normal ejection fraction?" Normal function moves 120 ozs of blood per minute. [#ASGDetroit](#)
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[AmyloidosisSupp](#): In [#amyloidosis](#) patients, heart fills with 2 oz, pumps 1-1/3 oz, ejection fraction is 67%, same as healthy. [#ASGDetroit](#)
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[AmyloidosisSupp](#): If heart can't pump out proper amount of blood, blood will pool in feet. [#ASGDetroit](#)
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[AmyloidosisSupp](#): If heart fills with 3 oz and pumps out 2 oz, that's an ejection fraction of 67%. [#ASGDetroit](#)
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[AmyloidosisSupp](#): If made of leather, doesn't matter how hard you squeeze, not much comes out because it couldn't fill with much. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Fill balloon with 1 qt. water, take off spigot, water shoots out under pressure. Not so if made of leather. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Most heart disease affects squeeze, unfortunately for [#amyloidosis](#) patients, their filling process is affected. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Heart spends 1/3 of second squeezing, 2/3 of second relaxing and filling with blood getting ready to squeeze again. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Protein reduces surface tension in urine, allows bubbles to form from agitation of falling into bowl just like soap in water. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Unique internist will see jump in cholesterol and wonder if there's an issue with kidney function. Happens rarely. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Hard to reduce cholesterol using cholesterol drugs in amyloidosis cases. Have to get the kidney function under control. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Recognizes fatigue is a common component with kidney amyloidosis but doesn't know why. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Total amount of water intake doesn't matter, it's the salt level. Dietary salt impacts swelling. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Drinking a lot of water doesn't matter very much. Holding water in circulation is function of protein and salt. [#ASGDetroit](#)
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[AmyloidosisSupp](#): About 25% of Amyloidosis patients require dialysis support. [#ASGDetroit](#)
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[AmyloidosisSupp](#): As kidneys leak protein, sends message to liver to make more cholesterol. Many patients show up with 350+ levels. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Swelling should be a major driver for patients to seek medical assistance. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Gravity also causes leakage if the protein balance is upset so swelling will show in feet more than in hands. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Damaged kidneys leak protein reducing amount in blood causing leakage. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Heart failure causes leakage because pressure is not high enough and it flows back. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Liver is factory that makes protein from dietary nutrients, creates albumin. Bad liver disease causes big swollen legs & belly. [#ASGDetroit](#)
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[AmyloidosisSupp](#): Protein asks as sponge to keep plasma from leaking out through the blood vessels as it moves through under pressure. [#ASGDetroit](#) about 9 hours ago



[AmyloidosisSupp](#): Now explaining the role of very thin blood vessels in oxygen & carbon dioxide exchange. Blood moves at rapid pace, 2ozs per beat. [#ASGDetroit](#) about 9 hours ago



[AmyloidosisSupp](#): High protein over time damages filter and over time can lead to permanent kidney damage that only dialysis can help. [#ASGDetroit](#) about 9 hours ago



[AmyloidosisSupp](#): Protein in urine indicates colander (kidney) is damaged. High protein in kidney affects purifier that cleanses filtered blood. [#ASGDetroit](#) about 9 hours ago



[AmyloidosisSupp](#): Protein in plasma are the peas. Colander has big holes from Amyloids. Water drains. Peas spill through & are lost down drain. [#ASGDetroit](#) about 9 hours ago



[AmyloidosisSupp](#): Amyloid punches holes in colander so peas pass through colander and goes down the drain, ie urine. Platelets won't pass through. [#ASGDetroit](#) about 9 hours ago



[AmyloidosisSupp](#): Kidney functions as a colander. What passes out is urine, what is needed stays in colander. Boiling peas & spaghetti passes out. [#ASGDetroit](#)
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[AmyloidosisSupp](#): [@MorieGertz](#) starts off surveying involved organs of patients at meeting--liver, kidney, heart, soft tissue. [#ASGdetroit](#)
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