

Longlife's Survey suggestions

Please contribute your research information. For your privacy, use the assigned number or make a username. Include all requested data points and keep a copy of the list below as an original. You may use an Excel or Word platform to track your information and send in on a weekly basis. Please be detailed on any symptoms you have had and those which appear to be effected by the use of Nilotinib.

REMEMBER that the intake of citric acid, citric fruits (grapefruit, oranges, tangerines, etc.) and some other foods will raise the sensitivity to N; meaning an increase in its effects which may nagatively effect your heart beat, even stop the heart. Be very careful if you plan on taking citric fruit and reducing the dosage of N at the same time. The more your read/study the scientific literature from the Internet concerning N, the safer you may be in the use of N to control / reduce dementia symptpms, as well as other symptoms, for which you have voluntairily decided to experiment with N.

Diet is a very important factor. If you decide to improve your diet, please include a list of items you start to intake as well as those items you decide to eliminate from your diet. This includes food supplements, medications, herbs, and the like. If in doubt, please communicate your doubts or questions. The following is an outline, if you could please follow this outline. You are free to include additional items/data but please do not avoid or reduce the list below. If you can not monitor your blood pressure, blood sugar, weight or any other data point, please note the same. These monitoring items are to be mesured either daily or weekly, whichever is most conveyant for you. The more frequent the better. We want to seethat you improve your conditions and quality of life. Blood Type test kits are under \$10 on Amazon.com, a one time cost. Blood sugar (Glucose) and pH test strips are also available for @\$15, some test strips will measure KETONE as well which is the best type of test strips to use urine testing (pH, Ketone, Glucose, as well as other measurements = @\$40). Cuff blood pressure test units are @\$25+ on Amazon.com.

I have filled in the data points below, as an example, of a male age 64 with Parkinson, as well as other metabolic disorders.

NAME OR NUMBER: [Assigned 0001, 0002, 0003 or make a user name of your choice]
DISORDER TREATED: PARKINSON
DISORDER MANIFESTATION DATE: 04 JULY 2014 by Physician (or self-diagnosed, etc.).
DISORDER SYMPTOMS: Instable right leg muscles, left arm paralysis, memory loss 45%, etc.
START DATE OF N: 01 JULY 2016
DOSAGE OF N: 150mg
X A DAY OF N: 2

Typical Stats
WEIGHT: 205Lbs / 93Kg
HEIGHT: 6'6" (2 METERS)
AGE: 64
SEX: M
BLOOD TYPE: AB+
BLOOD PRESSURE: 140/85
URINE pH: 6.2

DAILY EXCERCISE:
Aerobics 20 minutes a day to break a sweat everyday
walk 200 yards a day
weights, 25Lbs x 10 minutes/day

OTHER DISORDERS:

- A) high blood pressure (140/85),
- B) macular nerve degeneration (35% loss), glasses for far sightedness,
- C) diabetes II (7 years, BSugar 180-195),
- D) Left Kidney function loss 20% high Creatinina & Uric acid & protein count,
- E)

N prevention measures, Pre-Treatment:

Calcium Citrate, 200mg x 3/day
 Potassium Chloride, 100mg x 2/day
 Sodium Chloride, 10mg x 2/day
 Electrolyte drink, 1/day
 Aspirin, 80mg x 1/day

MEDICATIONS:

Aspirin; 80mg x 1
 Metformin; 50mg x 2
 Melatonin; 0.5mg x 1
 Glycine; 3Gr x 1
 Etc.

N Observations, detailed:

1 week	no change
2 week	no change
3 week	slight improvement in leg muscle movement only
4 week	leg movement normal, arm paralysis normal, memory improvement by 50%
5 week	memory normal
6 week	etc.
7 week	etc.
8 week	weight loss by 3% (198Lbs)
9 week	etc.
10 week	
11 week	
12 week	
13 week	
14 week	

THE FOLLOWING WILL HELP USE CONSIDERABLE TO ASSIST YOU IMPROVING YOUR LIKE STYLE AND HABITS, ALLOWING US TO SUGGEST WHAT NOT TO DO.

DIETARY CHANGES:

Note any changes you have made in your daily diet since taking N, such as:

I have reduced vegetable oil intake by 65%.
 i have started to intake 45Gr of coconut oil a day.
 I have reduced fried foods by 75%.
 I have increased water intake from 3 glasses to 7 glasses a day.
 I have reduced typical carbohydrate intake (potato, rice, bread, wheat products) by 35%.
 I have reduced intake of refined or table sugar by 80%.
 I have reduced salt intake by 35%.
 I have started to intake apple cider vinegar daily.
 I have increased legume intake by 70% (beans, peas, lentils, garbanzos, javas, etc).
 I have not changed protein intake except legumes and nutritional yeast.
 I have increased grains by 45%(Quinoa, Kiwichi, bran, wheat germ, ect.)

I eat liver (beef, lamb) or pancrease/kidney twice a week, fish three times a week, chicken or beef twice a week.

I eat fruit twice a day.

I eat vegetables two/three times a day.

I have started taking lecithin: 1,200mg x 2/day

I have started to take Omega3 concentrate: DHA, EPA; 450/320mg a day

I have increased vitamin E intake to 200mg/day

I have increased Vitamin d3, k2, selenium, zinc, complex intake.

I have increased intake of garlic, ginger, tumeric roots.

I have increased intake of culantro & parcelry with night meals.

I have increased intake of ground flaxseed

I have increased intake of walnuts and occasionally some other dried hard nuts/fruits.

I have increased intake of sunflower seeds.

I eat a considerable breakfast.

I eat a light lunch.

I eat a heavy diner.

Ect.

SLEEP/REST:

I have increased nightly sleep to 7 hours; arise twice to urinate instead of four times a night.

I have started Glycine and Melatonin each night.

I have started magnesium sulfate soaking every other night.

I continue to nap 30 minutes in the late afternoon (5-6pm).

I have started to feel more rested after the fourth (fifth, sixth) week of N experimentation.

KETONIC / AUTOPHAGY

I refrain from eating three hours before sleep-time each night (ie, eat diner at 7pm and go to sleep at 10pm).

I refrain from eating 12 hours a day (7pm-7am)

I intake 75% less sugar now.

I intake 90% less carbohydrates now.

ENERGY

I feel sluggish about every other day between 2pm and 5pm

My blood sugar drops considerably between 10am and 12am every other day.

I have had considerable energy since the second week of experimenting with N.

I no longer start to dose-off, nod-off, 30 to 40 minutes after eating meals.

Forum Posts

1:

[Ceridwen](#)

I felt very happy straight after taking it this morning more talkative but now feeling much more inflamed. Walking easier and felt more extroverted.

It may be psychosomatic but walking was much easier all day as was conversing. Tinnitus remained extremely loud on the right though with the ear blocking and unblocking a couple of times. Have now ordered all I need to put powder in capsules so please don't worry. I know it is not supposed to do anything for a while but compared this to a previous visit to a shopping center with my daughter where I could hardly walk it's incredible. Sometimes meds do work really quickly for me. I really didn't think that much about walking it felt like walking used to feel. We walked about 6 miles. I am very pleased. Keeping up with conversations was easy and relaxing.

My Nilotinib arrived yesterday. I think it has started giving me immediate results. Walking seemed easier and conversing. Memory still bad as is tinnitus but I was getting to a stage where walking was difficult. Yesterday I walked about 6 miles comfortably. It was like walking was normal again. Up till then I had been forcing it and having to concentrate. Placebo effect? Probably. I think it would take many weeks for the real effect to show. Memory and cognition are the most important things I have to improve.

<http://www.longecity.org/forum/topic/84008-nilotinib-group-buy/?view=findpost&p=774605>

2:

Park2009

<http://www.longecity.org/forum/topic/84008-nilotinib-group-buy/?view=findpost&p=771688>

1) I am taking Novartis Tasigna, I could get 6 boxes. Each containing 28 capsules of 150 mg each.

2) As on today I have consumed 50 capsules. I am still having 118 capsules, i.e 4 months supply.

3) My first dilemma was >> When to take it ?? Since product is not yet approved , doctors over here would take no interest in monitoring it or making any suggestions.

4) First 4 days I took it in the night with the thought >> Housekeeping / rouge protein scavenging in brain is claimed to be initiated while we are sleeping. But soon realised that I was getting uncomfortable and waking up with feeling of breathlessness.

5) After that I started taking it at 2 PM (Afternoon) each day. Again I felt breathlessness and it took me a while to figure out , I need lots of water with Magnesium and Potassium. So I have started taking lots of Coconut water and 2X 500 mg magnesium.

6) My tremors were reduced and I could take higher work load .But it is not a significant improvement , wherein I could claim reversal in Parkinson and possible dopamine regeneration.

7) I do feel thirsty after taking Tasigna, which lowers BP from my normal at 120/75 to 110/ 65 or 110/60.

After taking Gatorade or coconut water or EmergenC in at least 500 ml water BP is back to 120/75 and feeling of breathlessness is avoided.

As yet I do not have High BP issues.

8) Toronto is a cold place but soon I will start outdoor walking . Temperature has started moving up, that should help me judge if I can further improve .

9) Currently I try to have a walk on treadmill 30 minutes after taking Levodopa / Carbidopa or Tassigna . It is just 15 minutes walk at 2.5 miles/ hour setting. It puts medicine into circulation and after first 5 minutes of walking my tremors starts reducing, I leave treadmill in a fairly stable condition. But 3 hours later I do need Dopamine.

If I do not walk on treadmill , than it takes much longer to reboot.

I will write more about my observations in my Monday post.

5) Regarding Mg supplement It is hard pill of Magnesium oxide from Nature Bounty. I have taken Magnesium Citrate as effervescent powder , it seems it works better but it was expensive on a continued basis. I do take 1200 mg Calcium having 1000 IU D3. Calcium supplement is taken in the daytime , magnesium is taken in the night.

My Salt intake is not regulated. I do take it through my salad or stew . It is Sea salt non iodised. Claimed to be collected from waters of the mediterranean shores of Sicily.

Normally I take more salt than others in the family.

7) Coconut water available to me is packaged (Tetra Pak) . I am making sure I make my morning smoothie with coconut water. Between 6 am to 9 am I take 500 ml of fruit smoothie having 1 Banana and around 200 gm frozen Berries (strawberry + BlueBerris + Black berries) and Cherries. I add a handful of prewashed organic baby spinach to it and also Ginger. It helps me reboot me for the day.

My tremors are extremely low after taking morning LD/CD at 6 AM followed with Smoothie at 7 AM.

No chest pain or pressure felt in the chest with Tassigna (By now 50 days of taking it , 150 mg per day)

Mood is upbeat , no anxiety.

Resveratrol_guy : As yet no plans to increase Nilotinib to 2 x 150 mg.

I want to fix my bowels clearing first. It is bit out of control because after 15 days of taking Tassigna I went ga - ga and took liberty to eat all that junk which I used to take in the past. Since constipation is major issue with me or perhaps all Parkinson's patients. I will write separate note on that.

Write now it is 9 AM , Time for another Dopamine dose and then I will go to treadmill.

I believe Constipation is all Parkinson's patients nightmare. In my case I try to avoid it by avoiding following :

1) Do not take chicken. By now I am avoiding all types of meat products. I only prefer baked Salmon once or twice a week.

2) Milk also causes me constipation, hence I am restricted to taking yoghurt only. That too plain yoghurt or kefir.

3) Wheat also causes me constipation. Hence I take maximum 2 slices of bread/ day, made from sprouted multigrains having sprouted wheat as the main component. Bread is claimed to be preservative free and all grains are non GMO.

Rice is my main source of carb and I DO TAKE LENTILS.

With above mentioned scenario I was ok with 2x500 mg Magnesium oxide.

Once I started taking Tassigna. Just within 4 or 5 days, Constipation seemed to be non issue. So I had to stop taking magnesium to avoid running into diarrhea.

I became euphoric, so I started enjoying chicken, even though it was organic and limited to around 4 leg pieces a day. I have run back to magnesium at old level and stop taking chicken. Since Constipation reappeared.

Ever since I am trying to reestablish to a steady pattern but it looks it will take some time.

I have sufficient Tassigna for now, I am sure I will soon stabilize. And continue my little experiment with Tassigna.

1) When do you choose to take your 150 or 200 mg dosage (Early in morning, A/N or late in night, before going to sleep) >> I take it at 2PM each day.

2) After 4 or 5 days of taking it constipation was not an issue, I went euphoric and tried to push the limit. My suggestion will be >>. Do not do what I did. Do not make drastic changes in your food intake. 3) I felt breathlessness, I believe it was due to electrolyte imbalance. right now it is taken care or I should say it is non issue.

4) My tremors are definitely less than before, especially before noon and I am getting up in the morning with more energy than before.

Today I took count, by now I have consumed 73 Capsules of "N" x 150 mg. I have taken them at 2 PM each day.

It was only in the beginning first week, when I tried taking it at the bed time and ran into Low BP / Difficulty in breathing.

Thereafter it is always in the afternoon,

I have following observations :

My energy level has improved, I painted all the doors in my house with roller and flat paint brush. ! Cleaned the carpet in two rooms, within 1 week !

Suggestions from Logic/Long life / aaCharley were incorporated, Constipation related issues have taken a backseat, I am much better person.

Tremors are less but not gone. Energy level is definitely up. But I am not able to cutback on Levodopa / Carbidopa. It remains same. I need them every 3 hours.

Since I am fairly stable at a new level, I will try to shift 'N' to bed time.

I am not taking any antidepressants ever since parkinson's struck me i.e year 2009. I am regularly taking Cyclobenzaprine 10 mg at bed time with Levocarb CR 250/50 mg at bed time. I started taking it since 2013. Cyclobenzaprine is an excellent muscle relaxant tremor reducer as well as sleep aid for me , from now onwards I will try to stop taking it and have "N" instead at bedtime.

Longlife > I have Glycine in the the future plan , in case I miss my sleep , after knocking off Cyclobenzaprine.

Melatonin never worked on me. 5 HTP also did not help. Each time I took them , I ran into low BP and very uneasy feeling in the night.

will be always tempted to write in detail, my experiences / observations on how my system/body is behaving when I have adopted/incorporated suggestions given by you all. I believe let me have more days of having used Magnesium L Threonate instead of Magnesium oxide as suggested by you. Also how Glycine works with me , in my efforts to have better sleep , could I knock off , taking Cyclobenzaprine 10 mg each night. A suggestion from Long life (I am yet to start it). Cyclobenzaprine gave me tremendous relief in reducing tremors / having good sleep and relief from frequent urge to urination for the last 3 years. I am fully aware that Cyclobenzaprine is nasty stuff, no Doctor will like to prescribe it for a period of more than 1 month use, in case of muscle spasms. Also I replaced Banana in my smoothie to Avocado based on suggestions from aaCharley. Let me give myself a continued use of at least 1 month. Also as cautioned by Longlife I should not digress and stay focussed on "N" . So I will send my comments in a personal communication.

Regarding "N" : Here is my most recent personal experience / or you can say failed attempt to shift 150 mg "N" from 2PM each day to 2300 Hrs (11 PM) my bed time , when I also take 200 mg Levodopa Controlled release and Cyclobenzaprine. On 18th May I skipped my Tassigna at 2 PM and took it along with Livocarb CR 200 /50 mg at 2300 hrs. At that time I normally have more tremors than normal , since by that time it is almost 17 hrs since I woke up and started my day. Well I could slip into perhaps one of most relaxing sleep ! BUT It was a short 4 hours sleep. I got up around 3 AM ,it was a call to rush to bathroom and empty my bladder. I realized I was walking with firm steps , long strides! No baby steps!. At that time I was feeling very fresh and perhaps ready to run a marathon. Absolutely no brain fog ! But despite my best efforts I could not sleep , Again I realized I was able to change sides on the bed with absolute ease. But I could not go back to sleep despite my best efforts for next 1 hour. I got up and started reading news and many other articles on my ipad. My focus was sharp and I could read and absorb the content as I used to do in pre parkinson days.

Well It continued till 9 AM on 19th May and thereafter I lost the advantage. My tremors were uncontrollable despite having Dopamine at 9AM than at 12 Noon , So I decided to go back to Tassigna at 2PM and returned back to Levocarb CR + cyclobenzaprine in the night. Well again I had a good sleep and I am back to same level as in past two months.

Lesson I learnt : Either start taking "N" in day and also at bedtime, and than see what happens or else have a proper sleep aid in the night. Somehow I am determined to eliminate

Cyclobenzaprine with a safer product , Let us see how GLYCINE works . Again I wonder how it escaped my attention. Let us hope it helps. I know, If I get good 7 to 8 hours sleep, my parkinson symptoms are much lower in the day. Since I have limited "N" in Stock I am try to build it up , before embarking upon 2x150 mg per day regime. Today I will receive Glycine in 750 mg capsules , I will report back how it is going after perhaps after 1 week. Also to add more to confusion I also started taking certain probiotics with strains not taken before !

As on Today I have taken 97 Capsules, one each per day of 150 mg of "N" I am still left with 71 capsules.

That assures me, I am good for another 2 month and 10 days.

In the meantime another 168 caps have been procured for me. I will get them by July 2016. At that time I will take a call , if I continue taking 1 "N" per day or shift to 2 caps per day .

With 3 months and 1 week of taking "N" , I will like to sum up my observations :

1) My main issue is Tremors . To keep tremors under check , way back in year 2009 , I used to take Levodopa / carbidopa (LD/CG) 100/25 mg one tablet , 4 times a day and in the night it was 1 tablet LD/CD controlled released 200/50 mg.

2) Currently I need 2 LD/CD 100/25 mg tablets , 6 times a day + 1 tablets of Controlled release LD/CD at bed time. + 10 mg of Muscle relaxant . This was a 3 times jump in Dopamine intake over 7 years of parkinson's treatment.

3) Now after 9 weeks of Nilotinib use over and above regular intake of LD / CD as detailed above . I can say for sure My tremors have further reduced. But I can not reduce Levodopa / Carbidopa. I need it every 3 hours, otherwise tremors reappear, My energy level is better , ever since I started taking Tasigna. But I can say for sure, in my case I can not

4) Regarding Cognitive improvement , I believe it is not much an issue with me. Main issue is Motor function.(Tremors)

5) Regarding Constipation (Non motor) , it is an issue with me , But "N" has not made any impact on my constipation.

3:

[Der Springende Punkt](#)

have taken 250 mg for 4 days (it's not intended for me but wanted to test if it has some acute adverse events). I did not notice any side effects.

<http://www.longecity.org/forum/topic/84008-nilotinib-group-buy/?view=findpost&p=773312>

4:

Logic:

My own 'R&D' seems to show a slight but noticeable improvement so far.

<http://www.longecity.org/forum/topic/84008-nilotinib-group-buy/?view=findpost&p=777339>

5:

[centralFloridaMan](#)

I only began my research a month ago so while i am optimistic so far i haven't seen any results

<http://www.longecity.org/forum/topic/84008-nilotinib-group-buy/?view=findpost&p=786862>

6:

[Knasse](#)

I was in on [group buy](#) #2 and I think I am seeing some positive effects, so I would like to join [group buy](#) #4.

* I have been on 150mg/day of N for almost 2 months

* From the past I know I have better periods and worse periods so it is really hard to tell if things are really getting better, but I do think the improvements I am seeing is more than just a good period and placebo.

* The side effect I have seen is that I had some very itching rashes on my legs for a few days, but that is gone now. Itching rashes seems to be a well known side effect of N.

<http://www.longecity.org/forum/topic/84008-nilotinib-group-buy/?view=findpost&p=790355>

7:

David Watford

I have just embarked on a course , from buy #2. I don't expect to see any change for at least 6-8 weeks. Also, looking at the trial data, two things seem relevant to this view. The first is that several participants had a lower UPDRS score in the first month and in month 2, the score went up again, albeit temporarily. I infer from this that the effect could well be psychosomatic (and a good thing too!) but month 2 could seem a bit disappointing. The second thing is that the individual results were very variable. This seems to me to fit in with the results from other treatments.. like stem cell therapy.

Making the dose:

We are using jeweller's scales, a 3" square piece of greaseproofed paper, a 12" square of greaseproofed paper, some capsules (I think we are using size "0")

The scales are put on one side of the big square of paper. This paper will catch any spillage. We (that's my lovely wife, that is!) tare the small piece of paper and weigh 150mg. (or whatever).

Open the capsule and, putting the small piece of paper on the big piece, a knife is used to scrape the N into the long end of the capsule. The cap goes back on the capsule.

This is very convenient, meaning that I can travel etc. It also means I don't have to think about Parkinson's any more than necessary.

I received my N about a month ago. Prior to this, I discussed the situation with a non NHS (the UK National Health Service) neurologist and we decide to make an assessment of my condition and establish a baseline position. So 3 weeks ago, we carried out the motor section (Part III: clinician-scored monitored motor evaluation) of the unified Parkinson's disease rating scale (UPDRS). I also consulted a hematologist and had a blood test done. I haven't asked for the results for these, as it's the difference over time that I'm interested in.

I started with 150mg/day. As someone advised me, I took it with food at night to increase the effect. This was a mistake. I started getting side effects including those of indigestion and fatigue,

and these escalated to what I found to be intolerable levels. The literature says that grapefruit and food will possible triple the effective dose. So, at the end of two weeks I stopped and the side effects went away. Today, I am starting again with 50mg 2 hours after the last meal of the day. I'll try that for 2 weeks and if that's OK, I'll increase the dose. My body is still quite functional, so I am in no hurry to "fix" things.

<http://www.longecity.org/forum/topic/84008-nilotinib-group-buy/?view=findpost&p=790631>

8:

Oanh Nguyen

I started at 50mg/day as I am very sensitive to drugs. Did that for 2 weeks, all ok, then I went to 75mg/day for 2 weeks. All ok at 75mg, so went to 100mg for 4 weeks. I felt much better after that, so jumped to 150mg/day. Not good, had neck pain and didn't feel good, so went back to 100mg. 2 weeks later went to 125mg. Then went to 138mg, but fter 1 week my hubby and I decided my balance and gait were worse, and I didn't feel that good. So now back to 100mg and I am much happier. For me, more is not better.

<http://www.longecity.org/forum/topic/84008-nilotinib-group-buy/?view=findpost&p=790682>