

Foreword

(to the „Textbook of Tinnitus“ by Matteo de Nora)

Reflections on a 1000-day adventure in a research project

October is a very nice month in the Egyptian desert. It is also when the “Rally of the Pharaohs” takes place; an intensive ride in the sand where the main objective is not to get stuck or lost and to arrive at the right place before most of the others.

In 2004, like other times, I was participating and enjoying the concentration, the scenery, and the short nights in a camp, preparing the mind and the equipment for the next day. The next day, half an hour before the end of the stage, I passed the wheel to an impatient navigator who wanted his moment of piloting glory.

A few minutes later, the car went the wrong side of the hill, “rolled over” several times, and landed upside down at the bottom of the hill.

Whiplash, stressful emotion, and lack of oxygen to the ear (dissection of the carotid artery); I had just landed at the perfect scenario for developing something that was totally unknown to me until then: TINNITUS!!

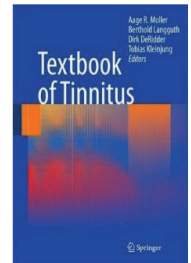
After 6 months of panic and useless wondering to find a cure, I was left with two choices: live with it or try to do something about it. Although accepting to live with it was probably the best cure at that moment, I chose to try to do something about it.

Not out of generosity or because I thought I was called upon the task by higher duties but because

- Unlike other pathologies, *time* was on my side: I was not going to die or get worse over time
- I had *experience* in organizing research
- I had the *motivation* to walk in other people’s life and ask them into a project I believed in
- I had the *time*, having sold my main business believing I could not lead as well anymore
- I had the *money*, and
- I did not want to regret that I had not tried

The “program” turned out to be a venture in frustration and hope, a balancing act between logic and instinct, and maybe a little but important milestone for successful therapies in the future. Also, and not surprisingly, it was a human adventure about people and their beliefs, their weaknesses, and their strengths. Here is how I remember it and what I would consider if it started again.

As an independent entrepreneur, I wanted to give some structure to my program, but without losing flexibility and making sure I would not “play doctor.” The main immediate points were



- How to finance it and through what entity
- How to choose the people
- How to choose and coordinate the research program, and my role in it, and
- How and when to end it, the businessman's "exit strategy"

How to Finance it and Through What Entity

- (a) An existing pharmaceutical company would seem the most immediate choice. However, their managers are guided by long-term survival of their companies and consequently by considerations such as short-term cash flow, risk, time to market of a product, and reimbursement by health care, and are often not open to innovation if it overlaps existing businesses (like in the case of new hearing aids).
- (b) Co-investing with government funding was not really an option. Tinnitus not being a life-threatening disease would not get a lot of attention. Moreover, government projects have a long bureaucratic approval process and once funded, they lack the flexibility to change directions during the research if the interim results so suggest.
- (c) An existing association was another obvious choice. Scott Mitchell, member of the board of ATA, has written many interesting articles and believes that public non-profit organizations appear to be the best vehicle for funding tinnitus research. Although I agree with him to some extent, it is normal that every time you are managing other people's money, you are somewhat restricted by present logic and paradigms, and have to allocate a lot of time and resources for explanations and accounting to "shareholders," in addition to public awareness, prevention, support to patients, etc.
- (d) *Direct funding to individuals by an individual*

As more individuals live long and achieve financial success, they reach a point where they feel they can use their money and their experience to make a difference in a field other than their own – and make it their "legacy."

Teaming up with one of them would be risky because these are in all likelihood strong personalities who bring into a program their style, their objectives, and their people, and since it is their "legacy" after all, often want a lot of exposure.

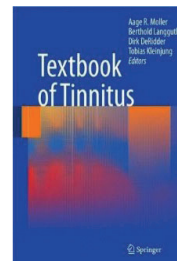
In addition, I wanted to try to bring together cross-border and interdisciplinary knowledge in a field where not enough was yet known to make it interesting to future participants (industry, governments, and associations) and had my own ideas on what was important – and what was going to make this possible.

Chances of improving were higher because we started from zero.

My program would be based on the idea that tinnitus research was still in a phase where to get to the next step it was better to stay away from too many "models," and that some of it had to be done by somebody who was willing to fail, make mistakes, change his mind, not understand, and ultimately not base his decisions on risk/reward but on people who were willing to work on a project for the right reasons and with the right attitude.

"Life is like a game of chess; the first moves are very important, but until the game is over you still have some good moves to play."

Anna Frank



How to Choose the People

I have always been involved in science – and yet know very little. My father was a brilliant scientist, with many researchers around him. I never tried to compete directly, but learned a lot from “back stage” and over the years. He had a sign in his office that said: “if you want to lose money spend it on boats, women and research.” Even if we have not spent a lot of time together, I must have taken that part from him!

The process of choosing the scientists whom I would have liked to meet each other and work together was very intuitive, but I can try to list a few characteristics that I think are common to successful scientists – they:

- Are optimistic but realistic
- Do not promise more than what they can deliver
- Are capable of giving bad news
- Take pleasure and attention in the growth of people around them
- Simplify and explain complicated things in a simple way
- See a problem and turn it into an opportunity
- Do not have what is called the “not invented here syndrome”: they listen with an open mind to other people’s ideas
- Recognize today’s assumptions and question them
- Look beyond the obvious
- Find a way to look at something new without rejecting the current concept
- Don’t look at an idea only to see what is wrong with it and how they can reject it
- Think and work a lot – genius ideas are a result of it
- Have a high sense of responsibility
- Always want to do things better and
- Try to do the best they can.

Some of these characteristics usually surface even in a short interview and I always saw some of them in the people who have at some stage participated in the TRI research program. I am naturally honored that they have accepted to work with TRI as I never took it for granted.

“The scientific mind does not so much provide the right answers as ask the right questions.”

Claude Levi Strauss

How to Choose and Coordinate the Research Program, and My Role in it

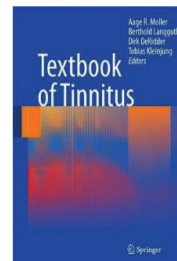
A traditional program would have three main components.

Leadership, to clearly identify the objectives so as to produce the results.

Organization, to identify the different functions and to allocate them to the best people.

Administration, to allocate the resources where and when necessary.

One difference in this case was that none of the participants was directly employed and that the relationship was based more on attitude and trust than otherwise. Each had their own existing activity.



The main objective was not to organize an effective research program but to encourage multidisciplinary, interdisciplinary exchange in the belief that the right people would seize the opportunity.

Personal interaction coupled with the exposure to different therapeutic areas would combine the knowledge without setting boundaries of research, and ultimately, individuals would choose their partners in the program.

Their partners would possibly be from different areas, different levels, and different countries and cultures, and that combination would increase understanding, innovation, and the feeling that the “mission” was doable.

Over time strategic groups and their performance obligations would form. Diversification would increase the effort of coordinating their work but would naturally identify specific areas of research.

Workgroups in pharmacology, neurostimulation, auditory stimulation, somatosensory modulation, and eventually tinnitus clinics (when the need for integrating research and clinical medicine became more evident) were formed, but these were based more on the individuals who chose to work together than on an imposed structure or organization.

Somehow the dynamics were quite different than those of a company.

Later I would have worked more closely to improve the connection between innovation and actual therapy. I knew that existing commercial compounds generated less problems. I also had learned that successful players design the most incisive clinical trials and were not necessarily hung up on publishing a lot.

The dynamics were a strange mix of what I had lived in the past, and my role was going to shape accordingly.

Rod Davis, coach of Team New Zealand sailing team, wrote an interesting article to explain coaching and support: The invisible hand. He says coaching is a weird combination of teaching, mentoring, being the hatchet man (at times), and being a nanny, throw it all in a blender and make something good out of it. Coaching, Rod writes, is not rocket science. In fact, it is not a science at all, it is art. Coaches provide the environment for driven talent to become champions. The ones with talent who take full advantage of the opportunities presented became champions.

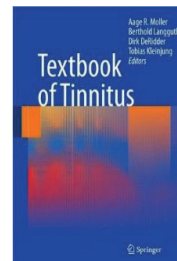
Environment means unloading distractions – It means create a belief in the ability to perform in tasks that are the most important to them. He adds that a big part of self-confidence is self-responsibility: if someone knows that it is up to him to be in control of his own destiny and knows he has done all that is needed to be ready, how can he not be self-confident?

This improves the chances of success, but there are no guarantees – there are thousands of pieces to the puzzle – but if the environment is right, the end result is certainly more likely to be positive.

Interestingly enough, two successive research coordinators failed in their mission, probably because they did not see the program the same way.

I was going to try and follow Rod’s “art,” keeping in mind that it was also my role – at least at the beginning, to add strong leadership and sense of the mission, just like Grant Dalton does with the very successful Team New Zealand.

“I came in understanding that the magnitude of the issues facing the country required that I put together a team that I could delegate a whole range of different tasks to and who would be able to work well together. Over the last 6 months I have relearned that lesson – that my most important job is to get the right people in the right place, give them the freedom to innovate and to think creatively about problems



hold them accountable for results, and make sure they are cooperating with each other and communicating on an ongoing basis.”

President Barack Obama, August 2009

How and When to End it

Basic research delivers the technology platform, the ideas, and concepts but they are often not at first accepted by industry or peers. This is the innovation gap and it needs to be bridged by the public hand. At a certain point, there needs to be an investment of the government to share the risk: political will is not only the weakest link in the chain, but also the hardest to fix. ¹

Governments, whose biggest expense is becoming health care, have a difficult task in choosing priorities. As an example, a very small percentage of cancer research spending would make a huge difference in other areas, including tinnitus.

Maybe a better way to look at it would be to present the issue in a more global way.

Now that the majority of researchers agree that tinnitus is a malfunction or reorganization that takes place with the neurons in the brain, its research implications go together with the understanding of other pathologies such as Alzheimer's or Parkinson's that are more easily understood as terribly detrimental.

Public nonprofit organizations should help bridge the gap to government involvement in addition to encouraging awareness and prevention.

Contrary to many, I believe that it is important that at a certain point the individual sponsor disappears. A more structured and long-term mechanism has to take place. People and programs should not depend solely on the sponsor.

In this specific case, the objective was to install new energy toward an “undervalued” problem and contribute to make it a stand-alone research area for medicine. Only time will tell how much has been achieved toward that end.

“You can have a dialogue about solving future problems all you like, but if you do not behave any differently when you go out of here, it won't make any difference.”

Dennis Meadows

“Limits to growth”

Conclusions

Strategy is about the future and then making decisions based on that. The worst thing you can do is not to have an opinion, and not make decisions. ²

More than ever, success depends on our ability to learn and to create value from what we learn.

In these times of uncertainty, scientists and physicians have to be agents of change in the right direction, accelerate science, advance medicine, and also direct it in a more integrated and patient-driven experience that is comprehensive to all.

Individuals still play an important role in sponsoring and discovery: it is everybody's task to create the environment and attitude for positive change.

Whether we made a change and the change was meaningful we will not know for years and maybe never. But I believe it would be a mistake to lose the momentum and coordination that TRI has created.

¹Peter Gruss, president Max-Planck-Society

²Alan Mulally, president Ford Motor Company

On a personal note, I have met some extraordinary people and scientists: although my tinnitus is still there, I believe that we have cured people who otherwise would still be suffering. I believe I will be cured in the next 3–5 years and that I will have that cure available before it enters the global market.

Is that enough?

It is one of the best things I ever did!

Matteo de Nora

