The things that truly matter…

by Sandra V. Navarra, MD, FPCP, FPRA

The patient is the best teacher. The Patient Partners© educational program actively involves patients with chronic inflammatory arthritis (RA, PsA, AS) who are trained and certified to teach musculoskeletal exam, and lupus patients who share their individual struggles and triumphs over their chronic condition. The program "doesn't force students to give patients a diagnosis, instead, it allows them to experience their patient's life and gain skills to be more effective caregivers" (Donald Kollisch) – these are valuable learnings which are not obtained from books or lectures even by esteemed professors. To share some feedback from appreciative medical students: "No matter how debilitating, these patients continue to live their lives to the fullest, transforming sheer disability to positivity" and "the program is not something I usually catch within the four corners of the classroom; from experiences like these I learn about the things that truly matter, inspiring us future doctors to strive hard in order to make our patients' lives comfortable as best as we can."

Each patient is a unique individual, and "time personally spent with the patient is the most essential ingredient of excellence in clinical practice" (Philip Tumulty). Voltaire (1694-1778) wrote "The art of medicine consists of amusing the patient while nature cures the disease", and modern-day Patch Adams reiterates "You treat the disease, you win or lose; you treat both the patient and the person, you always win no matter what the outcome". Emphasizing the importance of shared decision-making, Dave deBronkart (BMJ 2015) notes that "Medicine should let patients help improve care, share responsibility, and think for themselves." On a socially collective setting, the PEARL© (People Empowerment for Arthritis and Lupus) and LUISA© (Lupus Inspired Advocacy) movements of Rheumatology Educational Trust Foundation, Inc. – in partnership with Philippine Rheumatology Association – focus on patient-centeredness as key to improved patient outcomes and achievement of optimal patient well-being. For these patients, life can be fulfilling despite a debilitating condition.

A Precious Gem

PEARL theme song lyrics by Adrian Ramirez, music by Catherine Zulueta

A chance to share, a chance to care
A chance to be, whoever I can be
This is us, this is we…
A precious gem… this is me

I am my dream, not my condition
I'm not a disease, I am my volition
I am useful I know, so…Give me that chance to grow

This is life, and it's worth living
We see the light amidst the blur
We can face whatever life may hurl
We are strong, this is PEARL

See us shine as we open our shell
Listen to our stories to tell
It's our right to be respected
To dream and win as we're expected

Refrain:
A chance to shine, to love, to soar. A chance to live is what we long for.
We are friends, we are family. Look beyond what you see…

"Ultimately, patients need to find their own solutions and motivation and must take responsibility for their health; we must empower them to do just that" (Martha M. Funnell, MS, RN). Even in the terminally ill, the patient's feelings deserve to take precedence over the actual diagnosis. Let me share my personal experience and humble tribute to a patient named Frederick: " 'No more biopsy please…'

We sensed his frustration after the battery of tests, procedures and physician-specialists he had gone through… still without a diagnosis. Here was a young man at the pinnacle of his career, recently married and about to start a family, fully in control of his life … until this illness. The months of hospital confinement was an intricate intertwining of extreme science and delicate art, a roller-coaster ride through major as well as seemingly trivial yet crucial decisions i.e. starting steroids despite failure to arrive at a definitive diagnosis, painstakingly explaining the need for intubation in a fully awake patient, distinguishing the fine line between aloofness, aggression, sedation and simple narcotic side-effects and/or drug-drug interactions, and finally insisting to transfer out of the depressing confines of intensive care to a regular room where he can be with his loving family. It was a truly profound experience to witness this young man transform from the turmoil of uncertainties to anger to denial to stoic acceptance and valiant display of tranquility – despite being paralyzed from waist down! Wherever this ride takes us, it will ultimately be Frederick who will take control and make things happen in his time, in God's time."

We are forever students. Learn from, rather than dwell on, your mistakes. Attain the humility to accept that there will always be someone better than you, and that it can be a younger student. For the trainee: (1) The best time to make mistakes is while you are still under supervision of those who are more experienced, but remember not to commit the same mistake twice; (2) Make the most out of every patient encounter no matter how *toxic*, particularly unusual, challenging and complicated cases that will define you as a rheumatologist distinct from other subspecialists; the next chance to see a similar patient will likely be in your clinical practice where you must establish your credibility as a rheumatologist; (3) The simple mnemonics "IAP" may help guide management decisions: **I**nitiative in self-directed learning, constantly search for relevant resources and references. **A**nticipate and recognize possible consequences of your decisions including drug side-effects and drug-drug interactions. **P**rioritize decisions such as medications over diagnostics, refrain from ordering a test unless it will impact your treatment decision. Earn and enhance your patient's trust and confidence by clearly laying out immediate, intermediate and long-term plans for every patient.

A 2015 Medscape® poll of more than 292,000 physicians determined that **rheumatologists were the happiest subspecialists**! Here are the top reasons:

1. We are in control of our lives, practice and time. Thus, most of us know our children's names.
2. We get to take care of, and form long-term relationships with, our patients.
3. We are diagnosticians – the Sherlock Holmes of the clinic – often the court of last resort.
4. We have excellent therapies and get to see excellent results.
5. Rheumatology self-selects happy people.
6. We get lots of hugs from our patients – both literally and figuratively.
7. We practice the art as well as the science of medicine.
8. We take care of the whole patient, not just an organ.

The Rheumatologist is an effective **communicator**, able to explain, provide clear instructions, and discuss with the patient and family, peers and other healthcare providers, all aspects regarding patient care, and willingly assumes the "captain of the ship" role when the situation calls for it. The Rheumatologist is also an effective **motivator** – ready to take on timely and necessary social responsibilities as well as initiate and support advocacies beyond the clinics e.g. disaster preparedness and caring for our Mother Earth.

As a Filipino rheumatologist, I believe these are the things that truly matter…

References:

1 Don Kollisch is a family physician who moved two years ago from clinical practice at Dartmouth-Hitchcock Medical Center, in rural New Hampshire, to administration at Sophie Davis School of Biomedical Education at The City College of New York, in urban Harlem. For fifteen years he's written short fiction based on the lives of his patients--farmers, loggers and the like. He has had two stories published in *Dartmouth Medicine*.

2 Philip A. Tumulty. The art of healing. Johns Hopkins Med J. 1978 Oct;143(4):140-3.
"Time personally spent with the patient is the most essential ingredient of excellence in clinical practice."

3 Helman, Cecil. Doctors and Patients: An Anthology. Radcliffe Medical Press, UK. 2003.

On Voltaire (1694—1778:*) "The art of medicine consists of amusing the patient while nature cures the disease".*

4 *Patch Adams* is a 1998 comedy-drama film, directed by Tom Shadyac and based on Hunter "Patch" Adams' life story and the book *Gesundheit: Good Health is a Laughing Matter* by Adams and Maureen Mylander.

On Patch Adams: *"You treat the disease, you win or lose; you treat both the patient and the person, you always win no matter what the outcome"*

5 Dave deBronakrt. From patient centered to people powered: autonomy on the rise. BMJ 2015;350h:148. (Published 10 February 2015).

On deBronakrt: *"Medicine should let patients help improve care, share responsibility, and think for themselves."*

6 Martha M. Funnell, MS, RN . Patient Empowerment: A Look Back, A Look Ahead. The Diabetes Educator.Volume 29, Number 3. May/ June 2003.

On Funnell: "*Ultimately, patients need to find their own solutions and motivation and must take responsibility for their health; we must empower them to do just that."*

7 2012 Medscape poll http://www.the-rheumatologist.org/article/the-happiest-specialty-rheumatology-is-1/

BRYAN PARAS (16 Jan 2018)

- Female Churg Straus EGPA presenting as asthma "allergies" used up finances labs in Singapore but not diagnosed. Referred from Pulmo for STS, turned out to be neuropathy → thorough history, PE → EGPA → Rx: MPPT+RTX
- Male (from Korea) admitted at USTH-CD in 2010 [UST database search "SpA"+ septic arthritis, given MTX; Confusing data given by patient]. Now following up with Bryan [after looking for "rheumatologist" like Navarra and Briones] → Now dx: OA due to septic A
- Therese Sayo SLE nephritis flare following up with Bryan
- Challenges: Sacred Heart Hospital now taken over by MVP too restrictive "politics"
- Fulfilling to manage patients based on learnings from Rheuma training
- Patient care: Networking with other MDs for more efficient health care eg endorsed gout patient to Pelo in Bicol
- Pre-training "zero" SLE. Post-training: seeing many SLE patients, training enhanced self-confidence in managing SLE patients. Example: ANA -/ Ro & La+ clinically SLE patient [lab factor; Ro and La may be cytoplasmic not nuclear]
- Partnering with Arlene Vitug who frequently goes to Cebu.
- Differences in patient management by other training hospitals eg MTX administration. [Need to entice more trainees to UST]
- ARMS (with or without Lupus Roadshow) in Bulacan. IM trainees Bulacan Medical Center
- Patient (Yolanda Fernando) with AVN. BUT xray read as OA on 2 occasions (PCSO refuses to cover). Third x-ray by Radio grad of UST → finally interpreted as AVN, helped by personal communications with Bryan. [BP had radiocon on AVN]