

# DELAWRITER

The quarterly newsletter of AMWA-DVC

Delawriter Editors

Spring Edition, 2021

## A Moving Presentation from the 2020 Alvarez Award Recipient, Mary Elizabeth Williams

by Anne Erlich

Mary Elizabeth Williams is the 2020 recipient of the prestigious Alvarez Award. With great poise she presented, "Every Person is a Patient: Finding the Story in the Science" to attendees over the virtual conference platform in October. Williams captivated listeners with her presentation, which was candidly insightful into her battle with malignant melanoma. She addressed her emotional struggle with this fatal diagnosis, her determination to protect her children, and her professional career as a journalist and healthcare consultant.

In one defining moment, Williams' life changed forever. She outlined how thriving in the face of adversity was a balance of accepting the diagnosis and acting without hesitation. Within one week of receiving the life-altering news that she had cancer, Williams underwent surgery. Despite making a full recovery, the following year Williams found herself in a battle for her life. After receiving the sobering news from her oncologist that spots on her lungs were discovered, she enrolled in a clinical trial. She became one of the first ten people ever to receive immunotherapy for melanoma.

Williams recounted her newfound "patient perspective" and how she struggled with documents of "informed consent." She realized how informed consent is procedural rather than explanatory. Those pages and words of consent mean so much more to a vulnerable person. Williams recognized a prevalent gap in the clarity of what consent means for the sick person. Additionally, she spoke passionately about the need for more empathetic language for people who are suffering. Medical communications are about people, not just "clinical subjects," Williams declared.

Williams was a person living with cancer but still a wife, mother, and working professional. She acknowledged that her disease and participation in a two-year clinical trial did not take place on a "separate planet," and there was a need for her to give "context to her condition." And give context to her condition is what she did. Williams went on to author a book on her experience with metastatic melanoma and the immunotherapy clinical trial. She expressed her gratitude for the experience she had as a recipient of life-saving therapy and the impact of love and loss. In a very moving moment, Williams paid tribute to all those people who have been "sling-shot" into a health-crisis. She further applauded those healthcare providers and researchers who remain an invisible force that keep the world running.

Williams felt privileged to be part of the process of research. Her experience as a person with cancer in a clinical study gave her an unfamiliar perspective. After years of communicating health and science for national publications, Williams became the inside voice, advocate, and champion for sick people. Her defining message to those involved in communicating health is to embrace simple language that explains the data while giving dignity to those who participate in the process.

Anne Erlich, RPh, PharmD, is the principal of Write Market Access LLC in New Jersey and is a freelance medical writer specializing in continuing medical education and market access.

## Glycoscience: A New Language

by Linda Felcone

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#### Join the DELAWRITER

If you would like your byline to be seen by hundreds of AMWA-DVCers, consider volunteering to write an article for the Delawriter. Enjoy crafting emails for clients? Interested in learning how to format a

newsletter and have samples? Consider volunteering to become a designer and/or communication lead. Send your interest to [volunteers@amwa-dvc.org](mailto:volunteers@amwa-dvc.org).

### Quarterly Quotes

"Dogmatism and skepticism are both, in a sense, absolute philosophies; one is certain of knowing, the other of not knowing."

The field of glycoscience - which includes the study of complex carbohydrates attached to cell-surface proteins and lipids-is starting to come to fruition in biotechnology and medicine; therefore, it behooves medical writers to become familiar with the biochemical language. Blood typing depends on the distinct patterns of glycosylation. Several drugs on the market have already been developed using glycoscience. The drugs zanamivir (Relenza®) and oseltamivir (Tamiflu®) mimic sialic acid virus substrates, and peramivir and laninamivir are similar agents.

For a medical writer wanting to learn more about glycoscience, the NIH offers the free online updated textbook (3rd edition), *Essentials of Glycobiology*. The clear introductions to each section provide good overviews. Each chapter is written by an expert in the field. More importantly, it explains the current standardized nomenclature and symbols that have made glycobiology accessible to scientists with diverse backgrounds.

Glycoscientists can use a much-awaited common visual language to depict the three-dimensional structures of complex carbohydrates that we now know enable many biological processes important to medicine. Several barriers have recently been broken that had kept glycoscience almost invisible since it was introduced in the 1950s to explain blood types and allow for transfusions. Glycoscientists have always worked in fields separated into many silos. Recent developments, besides the much-needed common nomenclature, include glycoinformatics, high-throughput technology, and arrays to elucidate the sequences and geometries of branching sugar chains. New nanotechnology promises visualizing equipment that will allow scientists to see individual "trees" in the "forests" of glycans they study.

Compared with genetics, glycoscience is more complex because glycans make up branching structures synthesized post-translationally by enzymes in the endoplasmic reticulum and Golgi apparatus. Glycoproteins that have the same amino acid sequence but different glycans can have different physiological functions. Once released from the Golgi apparatus, lipid and protein glycoconjugates coat the cell membrane or diffuse into extracellular fluids. They change to meet the biological and chemical demands of the wearer. They can link to self or non-self components of the biological system. Information-bearing glycans can be present in various amounts and still have the same biological activity. Some of the "branches" of the submicroscopic "information trees" can be missing or broken and the process still works; so, it is not as straightforward as other processes scientists are used to describing and using.

Tissue-specific glycosylation of proteins and lipids partially explains how the complexity of human biochemistry can proceed from a limited genetic alphabet. The most conspicuous glycans are attached to proteins and lipids embedded in our cell membranes. However, at least half of the proteins in our bodies, including enzymes, are glycosylated. Surface glycans participate in fundamental biological processes such as fertilization, tissue differentiation, and absorption and metabolism of nutrients (or other substances, like drugs). They are also involved in disease processes such as infection, evasion of the immune system by both tumors and invading pathogens, and autoimmune diseases.

While the alphabet of genetics is the DNA code and the 21 amino acids it arranges, the alphabet of human cell surface glycans is 6 simple sugars: galactose, n\_acetylglucosamine, n\_acetylgalactosamine, fucose, sialic acid, and mannose.

The function of genes is fairly simple; in contrast, there are many different interactions between glycans and their protein binding-partners (lectins) that orchestrate intercellular interactions. They are also key to the constant wars, treaties and truces between our microbiome and invaders of the human body. The mode of entry of pathogens and their toxins into our cells is often mediated by the sugars on the surface of our tissues and lectins on coats of invaders such as bacterial cells and viral particles. It has been shown that some parasitic invaders can change their glycan structures to disguise themselves against the immune system. Other processes linked to sugars are communication within cells, and cell surface activities that incite the immune system (via major histocompatibility factors) to attack our tissues, leading to autoimmune diseases. It behooves medical writers to become familiar with glycoscience as the science advances. Glycoscience is like the English language at the present time - hard to learn, full of frustrating exceptions, but useful all over the world for precise communication.

In Europe, glycoscientist Lokesh Joshi of Aquila Bioscience developed a line of anti-COVID devices based on lectin-carbohydrate binding. If a writer wants to become familiar with the fascinating field of glycobiology, a good way to start is to watch Lokesh's TED talk on the subject, or to watch a presentation by Carolyn Bertozzi of UC Berkeley.

Complex glycans comprise the major post-translational modifications of proteins and lipids, and decorate the surface of every living cell. We need to know about them.

## References

1. Varki A, et al. [Essentials of Glycobiology](#), 3rd ed. Cold Spring Harbor Laboratory Press; 2015-2017
2. Joshi L. [Glycoscience, the sweet and sticky language of biology](#)
3. Kulkarni AA, Weiss AA, Lyer SS. Glycan-based high-affinity ligands for toxins and pathogen receptors. *Med Res Rev.* 2010;30(2):327-393.
4. Bertozzi C. [Chemical glycobiology](#).

*...rather than knowing.  
What philosophy  
should dissipate is  
certainty, whether of  
knowledge or  
ignorance." Bertrand  
Russell*

## Quarterly Pun

*"It's always good to  
get a smaller  
tournament under  
your belt so that by  
the time you get to the  
slams, you have a lot  
of experience."  
Serena Williams*

## AMWA-DVC Bookworms Virtual Holiday Meeting December 16, 2020

Don Harting and Monica Nicosia organized a virtual meeting for lively discussions of favorite books just in time for the holidays in 5 genres: humor, science fiction and fantasy, biography and memoir, fiction (other than sci-fi), and medical writing. Harting initiated the discussions on humor books with Reader's Digest Laughter is the Best Medicine, Friar's Club Encyclopedia of Jokes, and The Thurber Carnival. Helen Fosam began the discussions on Biography and Memoir with Becoming by Michelle Obama. Kathy Molnar-Kimber opened the medical writing books discussion with Jane Miller's The Chicago Guide to Writing about Numbers and Cole Nussbaumer Knaflic's Storytelling with Data; participants' favorite books included Laurie Lewis' What to Charge, James Clear's Atomic Habits and Angela Duckworth's Grit: The Power of Passion and Perseverance. Monica Nicosia provided a collage of audio and regular fiction books that prompted a lively discussion.

## AMWA-DVC Freelance Workshop March 13, 2021

by Katherine Molnar-Kimber

Lori De Milto presented "5 Habits of Successful Freelancers" to inspire all to enhance their freelance medical writing business. As clarification, habits are small decisions culminating in actions that you do daily. The 5 habits are confidence, excellence, marketing, management, and grit. As James Clear explains in Atomic Habits, your success is greatly influenced by your habits.

Confidence is believing that you have the ability to succeed and that you will succeed. Confidence helps attract high-paying clients, meet challenges head on, and take advantage of opportunities.

From clients' perspective, business excellence in freelancers means turning in great work on time while being congenial in all interactions. Or as Ed Gandia summarized, clients want "writers who understand their business and go above and beyond."

Building a marketing habit helps you attract your ideal clients, which lead to more repeat business and more referrals. The marketing habit covers both active marketing and continual less active marketing. Examples of active marketing include an updated LinkedIn profile, AMWA Freelance directory listing, website, networking, direct email, and follow-up.

Management of your freelancing business includes providing a professional infrastructure and performing work in a professional manner while adhering to professional behaviors. Professional freelance businesses use separate business checking account, credit card, invoices, and contracts.

Grit, perseverance, and mental resilience are considered more important in freelancing than just intelligence and skill. Angela Duckworth, author of Grit: The Power of Passion and Perseverance, summarizes the benefits of grit as happier, usually more optimistic, and are more resilient. Persistent pursuit of a goal despite falling short, screwing up, or slow progress demonstrates grit.

De Milto provided several tips for building habits, including:

- building a single habit at a time,
- creating a sentence that reinforces the time and place to implement the change,
- linking the new habit action after a current habit,
- choosing the appropriate time of day,
- providing a small reward for achieving small goals, and
- illustrating James Clear's 5-step process.

In summary, the 5 Habits of Successful Freelancers by De Milto provided refreshing examples and perspectives on the necessary attributes for building and maintain a freelance medical writing business.

Katherine Molnar-Kimber, PhD (Kimnar Group LLC, in Worcester, PA) is an independent medical writer who specializes in writing publications, CME, and grant reviews.

## AMWA-DVC Princeton Forum May 1, 2021

by Laura Skorina

AMWA-DVC hosted their annual Princeton Forum in an all virtual format on Saturday, May 1, 2021. This year's e-forum celebrated its 24th anniversary with a diverse program including sessions on Scientific and Clinical Publications by Kathy-Molnar Kimber, Microsoft Tips and Tricks by Dan Benau, Building Patient Trust by Angela Wagner, and Medical Writer Empowerment by Nancy Katz. With over 75 attendees from across the United States, the virtual program cast a broad net with interest across the medical writing field.

The forum also offered an informal lunchtime program called "What's Your Niche: Exploring the Medical

Writing Habitat". This session introduced medical writers working in different types of writing, who then shared their paths and experiences in their respective fields. Attendees were able to learn about different types of medical writing, the documents and deliverables, and their stakeholders, to potentially explore different career

options. This presentation should be helpful to writers new to the field, as well as the "well seasoned" wishing to expand their work. With limited time, the niche session could only touch upon a few areas in medical writing, which included Chemistry, Manufacturing, and Controls, Pharmaceutical Labels, Continuing Medical Education, Sales Force Training, Clinical Trial Documentation, and Patient Narratives. The niche session was a fast paced "speed dating" approach to share information and garner interest for further exploration for participants.

As with all AMWA events, the online discussions and chat panels were useful to share resources and other educational opportunities from both speakers and attendees. The organizers, Dan Benau and Darryl L'Heureux were pleased with the interest generated in the niche session and overall program and look forward to hosting more events in CMC and Sales Force Training in the next program year, either as virtual workshops or in-person events.

Laura Skorina, PhD teaches science courses at Temple University and Rowan University and is a freelance writer in scientific publications, CME, and patient-focused documents.

## UPCOMING EVENTS

### AMWA-DVC Annual Business Meeting on Monday June 28, 2021

AMWA-DVC's Annual Business Meeting will be held beginning at 7:00 pm EDT on Monday, June 28.

This all-virtual event will include announcement of results from recent elections, award presentations, "thankyou's", and introduction of new officers. More information about the meeting will come later.

Please show your support for our chapter by planning to attend.

### Medical Screenwriting: Crafting the Virtual Patient Case Scenario on July 15, 2021

AMWA-DVC will host a moderated discussion on interactive patient scenarios for accredited continuing medical education on July 15, 2021 from 6:00 pm to 7:30 pm EDT.

At the start the event, the program co-chairs, Marielle Fares, PharmD, MBA and Donald Harting, MA, MS, ELS, CHCP, will provide an overview of the event and introduce the speakers. A moderated discussion with fellow AMWA members who have written interactive patient scenarios for accredited continuing medical education will follow. The speakers include:

- Jill Herr, MD (AliveSim™ platform owned by Syandus)
- Scott Kober, MBA (RealCME platform owned by HealthCourse)
- Eve Wilson, PhD (DecisionSim™ platform owned by US HealthConnect)

Registration for this virtual event will open soon. Stay tuned.

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The Delawriter is published quarterly by the American Medical Writers Association-Delaware Valley Chapter

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