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Editorial

Regarding Parnassus

"It's tough to make predictions", averred Lawrence 'Yogi' Berra, "especially about the future". The Danish physicist Niels Bohr, said the same. This edition considers, in our small way, the past, present and future. How we did things in the past needn't influence how they're done in the present; and how we practise now shouldn't dictate the future direction.

In 1912, at the Harvard College Observatory, a prodigiously talented lady named Henrietta Swan Leavitt noted that distant stars, Cepheid variables like Polaris, pulsated with a regular beat. Furthermore by comparing their relative brightness, she could calculate where they were in relation to each other. From this, she devised the term '*Standard Candles*'[1]. In 1913, Vesto Slypher, working at the Lowell Observatory, detected a red shift in distant stars and realised that they were moving away from us[1]. Consequently Edwin Hubble, utilising these standard candles and red shifts, postulated two things: the universe was much bigger than had been supposed, and that it was expanding[1].

In 1936, George Lemaitre, a Belgian priest, mathematician and physicist, posited 'A Day Without Yesterday'[2] as part of his Fireworks Theory. The universe, he calculated, had burst forth from a primeval atom, or singularity. Lemaitre, also suggested that there should be smouldering remnants of the explosion still out there -cosmic rays. No one paid much attention. In 1948, George Gamow in his landmark *'Alpha Beta Gamma'* paper[3] (surely one of the cleverest titles ever published), speculated that these residual traces would now be microwaves. His paper was also almost universally ignored. Nearly 20 years later, Arno Penzeus and Robert Wilson, researching at the Bell Antenna in New Jersey, and unaware of Gamow's paper, were bothered by a ubiquitous hiss detected by the antenna despite all their efforts to eliminate it. It was, of course, the final piece of the puzzle - microwave radiation left over from the Big Bang. For this they won the Nobel Prize in 1978. Penzeus and Wilson connected the dots between Swann Leavitt, Slypher, Hubble, Lemaitre and Gamow.

Let's return to Miss Swan Leavitt. Her occupation in Harvard was merely that of a *computer*; that is someone who studied photographic stellar plates and from them made computations[1]. She was unusual, and not merely because of her stellar intellect. Her gender placed her in a regrettable minority of influential scientists. Marie Curie was another and was the first woman to be awarded a Nobel prize; the first person to win two Nobel prizes and the only person to have been awarded Nobel Prizes for both physics (Radioactivity,1903) and chemistry (Radium and Polonium,1911). For many women, the playing field just wasn't level, and for countless others, playing wouldn't be an option at all.

In his Oration, Professor Jim Dornan reviews the lot of women in history. I can recall, as a medical student, noting that all the consultants in what are now termed *craft specialties* seemed to be men. Even then I wondered, with the greatest respect to those great and good men, particularly in gynaecology, there surely had to be anatomical and physiological limits to their empathy? Professor Dornan and his generation were perfectly placed to amend this gender imbalance, and to their great credit, amend it they did.

This edition's Review paper is by Professor Tony Gallagher, an acclaimed international authority on simulation and an idea whose time has surely come. Professor Gallagher makes a compelling case for the future training direction of craft specialties, and how skills must be acquired and measured. The historical medical aphorism " See One; Do One; Teach One" won't pass muster. There is a viable alternative. Please read this edition's review paper to learn more.

QUICK RESPONSE CODES

Sharp-eyed readers will observe that the journal's back cover now includes a small black and white square. This is a 'Quick Response' (QR) code. Its purpose, we envisage, is to facilitate access to the journal from your smartphone. It's a work in progress, but if you have the software (and it's readily available as a download), please try it. In successive editions we will increase its functionality.

EDITORIAL APOLOGY

As happens on occasion, a busy, and much in demand contributor was unable to meet our current publication deadline, and his apology was fulsome. Consequently, as the 'Grand Rounds' piece was already entitled, 'The Chest Radiograph' and would form part of a greater sequence, I elected to write, at a minute to midnight, something myself. I hope it will be of some use to students and examination candidates.

Please keep sending me your good papers.

Barry Kelly

Honorary Editor

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2. Farrell J. *The Day Without Yesterday*. New York. Basic Books. 2010.
3. Alpher RA, Bethe H, Gamow G. The origin of Chemical Elements. *Physical Review* 1948; **73(7)**: 803-804

NORTHERN IRELAND
RARE DISEASE PARTNERSHIP

The Northern Ireland Rare Disease Partnership (NIRDP) is a unique partnership of those living with a rare disease and organisations representing them, with clinicians and other health professionals; science and industry; health policy makers and academics.

A disease is "rare" if it affects 5 or fewer in 10,000 of the general population. There are over 6,000 recognised rare diseases; as medical science advances, more are identified. 1 in 17 people in the UK is likely to be affected by a rare disease at some point in their lives; that's almost 106,000 people in Northern Ireland.

Collectively, rare diseases are NOT "rare"!

Although these conditions are all individually rare, we find that affected individuals share many of the same experiences. Patients with rare disorders can face a very long and convoluted diagnostic journey. They may see many doctors and other health care professionals before getting a diagnosis. When they do receive a diagnosis they often find that very few healthcare professionals have heard about their condition, or know much about it.

And from the doctor's perspective, managing a patient with an unknown condition, or a rare disease can be a complicated, even daunting task!

Some aspects of diagnosis, care and treatment can be very highly specialised, and may even be available in only one or two localities in the UK- even in the world. But much of the support and help that is needed by patients day to day can be relatively routine, and can be provided from existing services. We know, too, that the patient experience is greatly improved (even transformed) by a willingness on the part of their doctors and other health care professionals to listen to them, and to their carers: to find out something about the condition and to seek advice and help from the specialist or specialist centre, even if he, she, or it is "across the water" or even further afield.

The NIRDP aims to advocate, educate and innovate for those living or working with rare diseases. We aim to work together to find practical ways of improving the quality of life, treatment and care for those living with rare diseases right across NI- in every GP practice and political constituency, in towns and townlands. Our membership includes people with over 30 different rare conditions, ranging from the very rare disease to the relatively well recognised, like Motor Neurone Disease, Spina Bifida, Muscular Dystrophy or Huntington's disease; and a range of specialist nurses, physicians, researchers, and organisational representatives. This mix facilitates information and knowledge transfer, and mutual support- whether that is families facing similar difficulties; families supporting their clinicians to promote improvements to service delivery; or clinicians adding weight and expert knowledge to calls for policy changes.

Membership is free. It gives access to a growing network of knowledge, information, help and support; and to ways of influencing and making views known and heard. Please encourage your families with rare diseases to make contact with us; please contact us yourself if you feel we can be of any help; and most especially if you would like to contribute to any aspect of our work. We are stronger together!

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